No patient is an island

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The dangers of disease specific aid programmes

PERSONAL VIEW Roger England

Last week saw the launch of the new International Health Partnership that Prime Minister Gordon Brown hopes will accelerate progress towards achieving the United Nations’ millennium development goals for health (see News p 532). Will the partnership make a difference? Certainly, the joint press release with Chancellor Merkel of Germany made the right noises (www.number-10.gov.uk/output/Page13047.asp). Politicians are realising, perhaps, that throwing money at countries through disease specific global programmes might make good press, but it is not the way to help Africa.

Although international aid to developing countries for health has doubled to $14bn (€7bn; £10bn) since 2000, much of the increase is tied to individual diseases and is delivered outside of recipient countries’ planning and budgeting systems, causing big problems for the recipients. Money for combating HIV and AIDS is the worst. This now exceeds the whole health budget of many of the recipient countries, such as Uganda (figure). It distorts countries’ efforts to deal with their problems, because most of this new aid is delivered “off budget,” resulting in separate plans, operations, and monitoring—all in parallel with government systems. Just as countries are strengthening their budgeting processes and linking planned expenditure to activities, donors are earmarking aid to their own priorities, led by lobby groups in rich countries and donors are strengthening their budgeting systems, causing big problems for the recipients. Money for combating HIV and AIDS is the worst. This now exceeds the whole health budget of many of the recipient countries, such as Uganda (figure). It distorts countries’ efforts to deal with their problems, because most of this new aid is delivered “off budget,” resulting in separate plans, operations, and monitoring—all in parallel with government systems. Just as countries are strengthening their budgeting processes and linking planned expenditure to activities, donors are earmarking aid to their own priorities, led by lobby groups in rich countries and their acquiescence of compliant politicians.

The main providers of aid for HIV and AIDS are the US President’s Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the World Bank’s multi-country AIDS programme (MAP). Each imposes its own priorities, plans, and reporting requirements, thus massively increasing the administrative burden on countries. Much MAP money is channelled through national AIDS bodies operating independently from health services and indeed has encouraged the proliferation of these bodies. Global Fund money comes with complicated and inflexible procedures that start with the grant application. And PEPFAR operates largely independently of recipient countries and uses the large scale importation of US organisations.

Countries know that until HIV and other disease specific services are integrated within general routine health services there will be duplications not synergies, and they will not be cost effective or sustainable. As it is, all this money is achieving little: HIV prophylaxis is used in only 9% of pregnancies among HIV positive women, for example.

What is missing is strengthened national healthcare systems that can deliver the range of services that countries need, according to their own priorities, not those of international lobby groups. No one is funding this adequately, and no international body is equipped to provide the technical support countries need. The obvious candidate, the World Health Organization, suffers from serious constitutional and institutional flaws and is chronically under funded.

What can Mr Brown’s new International Health Partnership do to redress this? Firstly, participating donor governments can stop funding global programmes that do not put their money through recipient countries’ planning and budgeting processes—withstanding money from the Global Fund, for example, until it joins the sector wide, basket fund arrangements that countries have established to combine donor and domestic financing.

Secondly, the partnership can press for the Global Fund to become a truly global health fund—not a three diseases fund—so that financing can be better coordinated even before funds get to countries and so that countries will have more predictable funding with which to invest in longer term plans.

Thirdly, it can provide real support to countries that are seriously reforming their systems. Such support must extend beyond encouragement and advice: it must start with paying for the extra costs of decentralisation and of moving services out of government to independent they should use aid money to pay staff more if they perform. It doesn’t matter whether the staff are employed by public or private organisations or are self employed. Already, 60% of health spending in sub-Saharan Africa is private, and reform minded governments are looking at how purchasing those services can raise quality for public consumers.

Finally, the partnership can lead a complete rethink of the millennium development goals, not because we are not going to meet them, but because they are more trouble than they are worth—and always were. They were cobbled together to make politicians look grand for the UN millennium declaration in 2000. Targets were set in the absence of any idea of how they were going to be met, how much it would cost, or where the money was coming from. The “one size fits all” target percentage reductions mean that countries that have achieved a lot in the past have big difficulties in meeting the goals, and gains (or lack of them) take no account of distribution across socioeconomic groupings. They are a factor in the rise of disease specific global programmes instead of sector-wide reforms.

We will not achieve better health care for the world’s poor without better national health systems to fund and deliver it, and we will not achieve that without a better international system for aid. Disease specific programmes do a disservice to this ambition, and the International Health Partnership must not only recognise this but be bold enough to act.

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An inconvenient truth

As a child I was good with a knife. Preparing 4 kg of potatoes in 10 minutes—anything was preferable to milking the goat. No ready meals for us. At school the air was thick with the smell of burnt toast and the sound of bubbling cauldrons of custard, for home economics classes were compulsory. At university I worked in a restaurant washing dishes, graduated to vegetable preparation, and eventually specialised in making the starters. Later, armed with a Delia Smith idiot’s guide cookbook, I discovered a passion for food and cooking. Cooking, however, has become mere “entertainment,” ever more voyeurism, and about the celebrities rather than the food. We are losing our food culture.

This is the era of the convenience meal in all its guises. Our main streets are full of takeaways: fish and chips, Chinese, kebabs, pizza, and Indian. But at least there is a degree of honesty in these colourful shop fronts. We pull into the supermarkets and stuff our trolleys with ready meals of couscous, duck, Jambalaya, deluding ourselves that this is proper food, but these are just takeaways too, processed imitations of real food, stuffed full of hidden calories, salt, and preservatives.

But our children fare the worst; in a society that venerates the needs of children they have become culinary Napoleons. They eat only what they like, and so what they like becomes all that is offered. Junk explanations are offered: food “allergies” or “intolerance.” Behind the closed doors of many of our most affluent households, no one cooks, and kids get processed foods, with fat chance of escaping obesity or eating disorders. Our society is “allergic” to accepting responsibly, so it is all the fault of advertising and the food industry. Our children’s diet is parental passivity at its worst. All the excuses about time or cost are just that: excuses. We got what we wanted—wealth, comfort, and, above all else, convenience—but on the way we have lost much.

The Lancet has just published evidence that food additives adversely affect conduct (doi: 10.1016/S0140-6736(07)61306-3). This is not much of a surprise. But the real issue is our consumption of processed convenience foods. We need to value our traditional food culture, reconnect with food production, and see cooking as importantly as we do the “three Rs.” Schools should relinquish their blinkered obsession with academic performance and instead be filled with the smell of burnt custard. Likewise, families should give up the pointless merry go round of tutors and extracurricular lessons and use this time to prepare food together. Children can learn to do something positive with knives rather than just seeing them as something that teenage gang members wield. Let them cut their fingers and burn their hands. Believe me, this is considerably safer than milking a goat.

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Forceps at dawn

In one of his early films David Niven was a doctor in an Alpine sanatorium. Barbara Stanwyck was his patient, a beautiful concert pianist dying from consumption. When she became distressed in the night he appeared immediately, hair immaculately parted, his face filled with debonair concern.

This scene from an otherwise forgettable movie often comes to mind as the phone beside my bed lets rip with its infernal ringing and vibrating. (At 3 am, why do the registrars call my mobile instead of my home number? I suppose I should take it as a sly compliment.)

You don’t go to the labour ward in pyjamas. It will only amuse the midwives, frighten the patient, and disillusion the trainees, who will assume your valet has resigned. In fact you rarely need to rush. The more urgent the call, the more likely the registrars are to have sorted things out by the time you arrive. But you keep slip-on shoes ready and a shirt with cufflinks inserted. At traffic lights you do up your bow tie. Best to be legal.

After 25 years of this, your emotions are predictable. You start with self pity, particularly if it is raining and your up-and-over garage door empties itself down the back of your neck. You become sanctimonious as you drive past drunks emerging from nightclubs. If you are going to deal with a nasty complication you tense up, thinking of worst-case scenarios.

Usually, though, you are simply going to supervise a rotational forceps or breech delivery—things you did as a registrar without bothering the boss. You think dark thoughts about the epidemiologists who turned these procedures into rarities, and wonder what will happen when you and your ageing contemporaries retire.

You hurry past the smokers (always at the door, whatever the hour) and into what feels like the last reel of a western. “I know you’re there. I’m coming to get you.” For baby and professor, the stakes couldn’t be higher. One false move and we’re both in trouble. Too often, you ease the registrar aside.

As the birth ends you feel a sense of wonder, even after all these years. You drive home remembering the parents’ faces and baby’s name. A silly smile, yes. A little tear? Surely not. Dash it, you’re supposed to be debonair.

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Live and let die

Stefan Zweig was an Austrian writer who was a close friend of Freud's. He occupies more or less the same place in German letters as the literary doctor Somerset Maugham in British—that is to say, he is viewed with suspicion by the literati because, although brilliantly intelligent and immensely cultivated, what he wrote was so intensely readable. To be really great, at least nowadays, you have to be difficult to understand. Like Somerset Maugham he wrote short stories and novellas in which the most intense passion is described with almost clinical detachment. Like Maugham, Zweig understood that human nature was best examined in the petri dish of marginality and social isolation. Like Maugham, he is able to conjure an atmosphere in a few simple words.

In his novella Amok the narrator—obviously Zweig himself, just as Maugham is often his own narrator—describes a shipboard meeting with a German doctor who has been working in what were then (in 1912) the Dutch East Indies. The doctor avoids all human contact on board ship and meets Zweig by accident in the dead of night. He then tells Zweig his story.

Fleeing disgrace in Germany, where he had had a once promising career, he signs up to the Dutch colonial service and is posted to a remote station in Java, which he does not leave for seven years. Deprived of European company, one day a very superior English woman, the wife of a rich Dutch merchant who is away on business, comes to his remote station to ask him to perform an abortion. In her husband's absence she has had an affair and wishes to preserve her reputation.

The doctor has no moral qualms—he man runs around stabbing people, the doctor offers to perform the abortion if she will sleep with him. She refuses his offer with contempt and has an abortion performed by a local midwife. Too late, the doctor is called in to watch her die from haemorrhage and infection. On her deathbed she extracts a promise from him never to reveal what has happened to her.

Going home penniless and morally broken, the doctor rejects Zweig's feeble offer of help, inherently inadequate to the situation.

“Among the ‘rights of man’ there is a right which no one can take away, the right to croak when and where and how one pleases, without ‘a helping hand’.”

Theodore Dalrymple is a writer and retired doctor who has helped women before in this situation—and though strictly abortion is illegal, the law permits him to make up some kind of medical excuse to perform it. The woman asks that he leave the colony as soon as he has performed the operation and offers him a sum of money that will yield the equivalent of his pension. In a moment of madness, after which he acts like a man suffering from amok, the mental condition in which, because of an emotional crisis, a previously sane man runs around stabbing people, the doctor offers to perform the abortion if she will sleep with him. She refuses his offer with contempt and has an abortion performed by a local midwife. Too late, the doctor is called in to watch her die from haemorrhage and infection. On her deathbed she extracts a promise from him never to reveal what has happened to her.

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And the doctor does indeed commit suicide.

Ten years after the British publication of Amok, Zweig, having seen the writing on the wall in his native Austria, was a British subject living in exile in Brazil. The Nazis having scored victory after victory in Europe, Zweig thought they would win the war, and he and his wife swallowed a fatal dose of Veronal, the very sleeping draught the doctor in Amok had used regularly to procure sleep from his troubled conscience.

Theodore Dalrymple is a writer and retired doctor

**MEDICAL CLASSICS**

**The Plague By Albert Camus**

First published 1947

Camus’s classic account of the plague in Oran, a coastal city in Algeria, is a moving portrayal of love, longing, exile, abandonment, loneliness, and the tragedy of separation. Some consider it an allegory of Nazi totalitarianism; others as a commentary on existentialism, the absurdity of life itself. Yet it is a lifelike description of the scourgé of an epidemic and the futile efforts of Dr Bernard Rieux to cope with horrendously ill individuals and the spread of disease. Rieux, who had no effective treatment, often stayed at his patients’ bedsides through their entire excruciatingly painful and prolonged deaths. The narrator (Rieux himself) sums up his thoughts thus: The tale he had to tell could not be a final victory. It could be only the record of what had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers.

Would today’s professionalism match Rieux’s unselﬁsh, dogged persistence and the personal risks he took in treating highly infectious patients? If anything we now seem to have far more opportunities to deal with pestilence. Examples readily spring to mind: HIV, bird ﬂu, Ebola, anthrax, smallpox, and recrudescent polio. In these outbreaks most doctors never faltered in their professional commitment to treat highly contagious patients; many took risks of transmissible infections, needle sticks, and handling of contaminated specimens.

I wonder whether this time honoured spirit of professionalism will survive the social and organisational changes of modern medicine. Rather than stick with patients through thick and thin, many doctors work exclusively by the clock and, like Cinderella, morph out of their doctor role when their shift ends. The list of these new medical “shift workers,” including intensivists, emergency physicians, and hospitalists, keeps growing. It also encompasses the latest generation of house officers, who become excellent short term problem solvers but rarely see other doctors sticking with patients throughout their battle with illness and are rarely able to do so themselves. Will a new “shift mentality” impede doctors’ commitment to the venerable tenet of the profession to serve the sick? Have we adequately pondered the unintended consequences of a medical system that forces house officers to leave their patients’ bedside and to turn their care over to someone who may have less personal investment in their recovery? Will these changes usher in an altered professionalism that we had never anticipated?

Camus reminds us that there are dead rats everywhere, that epidemics, wars, hurricanes, floods, and tsunamis create refugees, illness, and untold human suffering. Despite social, political, and scientiﬁc progress these threats never end. All require an enormous cadre of physicians who will ignore the clock, grab a bottle of penicillin, and rise to the challenge. Will they show up? Jerome Kassirer, distinguished professor, Tufts University School of Medicine, Boston, Massachusetts jpkassirer@aol.com
No patient is an island

A radio series about the work of ethics committees, which demonstrates the web of personal and professional relationships that surround the patient journey, impresses Daniel K Sokol

David, a middle aged man with severe learning difficulties, has high grade lymphoma. With prolonged chemotherapy, the chances of cure are roughly 50%. The treatment, however, may prove traumatic for David, who is unable to speak and who earlier experienced great distress when undergoing computed tomography. Might palliative care be a better option?

Although clinical ethics committees (CECs) are a desirable and increasingly common addition to healthcare institutions in the United Kingdom, they are, in my experience, underused. “We need more cases” is an oft-heard refrain among committee members. Whatever the reasons for this paucity of referrals, BBC Radio 4’s new series of Inside the Ethics Committee should raise awareness of the existence of CECs and convince even the ethics-sceptic clinician that reasoned discussion of a case can lead to fruitful conclusions.

Hosted by Vivienne Parry, each programme presents a thorny case and examines the ethical issues with a panel of three experts, usually a mixture of clinicians and ethicists. The astute reader will already have noted that the resemblance to an actual CEC is limited, given the differences in size and constitution. It is thus a mini-committee, devoid of chaplain, lay person, and the other usual suspects. Another difference, and a great strength of the programme, is the involvement of key participants in the case. In the case of David described above, we hear from his psychiatrist, the manager of his care home, and a hospital clinician. In the second case, involving a severely anorexic 27 year old woman (Kate) requesting palliative care, we hear from the patient herself, her initial desire to improve her ballet dancing, and her descent into a world of fear, hopelessness, and guilt. We picture the situation through the words of Kate’s mother and the psychiatrist who treated her following a paracetamol overdose. These multiple narratives highlight the complexity of the situation, the real life nature of the case, and the fact that patients are not isolated units, but embedded in a web of personal and professional relationships.

No patient is an island, as the poet might have said. The various voices also prompt us to reflect on what is easily forgotten: that CECs deal with matters of consequence and that, to assume this considerable responsibility, committee members should be suitably trained.

There is a danger, in this kind of programme, of digressing from the matter at hand. Vivienne Parry, the guiding Virgil, excels in her role, keeping the discussion focused and flowing. In the case of David, she asks perceptive questions on the pitfalls of substituted judgment and the subjective nature of assessing another person’s quality of life, a theme that extends into the anorexia case. There is indeed increasing evidence that we are poor assessors not only of other people’s quality of life but also the quality of our own life in the future. Harvard psychologist Daniel Gilbert, in Stumbling on Happiness (London: Harper Perennial, 2006) remarks that “most of us have a tough time imagining a tomorrow that is terribly different from today” and, to illustrate, “teenagers get tattoos because they are confident that DEATH ROCKS will always be an appealing motto.”

With the exception of a few comments, the guests are articulate and well informed and the mix of expertise adds a welcome variety to the comments. They raise issues, such as the evaluation of best interests, the limits of respect for autonomy, and the status of advance directives in psychiatry, that although only touched upon in the programme could be developed further in a discussion group. One guest, for example, mentions the case of a competent patient with anorexia nervosa who, fearing that she will irrationally refuse treatment when below a certain weight, asks the health professionals to treat her if this should happen. This is sometimes referred to as a “Ulysses contract,” recalling Ulysses’s request to be tied to his ship’s mast before passing the island of the sirens and not to be released whatever he may say or do. Such contracts raise a wealth of practical and philosophical issues about desires, rationality, and autonomy.

So what happened to David? The actual CEC decided against chemotherapy, allowing David to return to his care home. Inside our mini-committee, two members concurred, and one disagreed. As for Kate, both CECs rejected her request for palliative care and suggested a compromise solution. The third programme examines the case of a healthcare worker who sustained a needle-stick injury when treating one of the unconscious victims of the 2005 London bombings. Can she request an HIV test without the patient’s consent?

Although I shall not tattoo “Inside the Ethics Committee rocks” on my arm, this is an intelligent and engrossing programme.

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Competing interests: One of the guests in the series is a colleague of DKS.