

OBSERVATIONS

BORDER CROSSING

Enlist the patients' help

Supporting people to self manage chronic disease could help reduce its global burden

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Next week the United Nations will unveil its blueprint to tackle the global epidemic of chronic non-communicable disease. Its summit meeting will focus attention on rapidly rising rates of disease, which threaten economic and social development in poor countries and are putting unsustainable burdens on all countries' health systems (*BMJ* 2011;343:d5762, doi:10.1136/bmj.d5762).

The UN's initiative has provoked much debate. The decision to confine the focus to cardiovascular disease, diabetes, chronic respiratory disease, and cancer was widely criticised. Mental health should have been on the list, because it's the coexistence of depression and fatigue that erodes patients' quality of life and accounts for most of their loss of productivity. Obesity, musculoskeletal disorders, and neurodegenerative disease should have been included too, and more emphasis should have been put on drivers such as population ageing, malnutrition, and the wider determinants of health.

Although there has been broad consensus on the "asks" from the summit (*BMJ* 2011;342:d3823, doi:10.1136/bmj.d3823) and the need for multisectoral action to tackle shared risk factors, successive "tinkering" to the draft outcomes document has led to accusations that it lacks teeth, that rich countries are unwilling to help poor ones, and that the interests of transnational industries have held sway (*BMJ* 2011;343:d5836, doi:10.1136/bmj.d5836; 2011;343:d5336, doi:10.1136/bmj.d5336).

Amid the controversy scant attention has been paid to the patients. This is surprising. There is convincing evidence that supporting patients with chronic disease to self manage their conditions and make informed choices about treatment is a good way to improve the quality and safety of care and reduce costly and inappropriate over use of healthcare resources (*BMJ* 2011;342:d1513, doi:10.1136/bmj.d1513). Their input into service design and delivery and research agenda is valuable too.

Most of the research on patient empowerment and shared decision making has been conducted in rich countries, where its promise is recognised by policy makers (<http://resources.bmj.com/bmj/about-bmj/article-clusters>, "Shared decision making") and the principles incorporated into new integrated care initiatives. In the United States the "high and accelerating increases in the cost of health care and the limited roles of

patients in decision making central to health and health care delivery are too real to ignore," argues a commentary on the new "accountable care organisations" (*JAMA* 2011;305:1800-1, doi:10.1001/jama.2011.547). In the United Kingdom general practitioners are being urged to help patients with chronic disease play an active part in managing their own conditions (*BMJ* 2011;343:d5623, doi:10.1136/bmj.d5623).

But there is also good evidence, from a wide range of community based studies in low and middle income countries, that engaging patients and supporting them to play an active role in managing their disease holds promise in all countries, researchers at the George Institute for Global Health underline (www.georgeinstitute.org). The institute, which has hubs in Australia, China, India, and the UK, has spent the past 12 years investigating innovative affordable strategies for managing chronic disease, mostly in disadvantaged populations in low and middle income countries.

At a parallel meeting in New York next week, to which UN summitters are warmly invited, the institute will launch a new policy document, *Patient Empowerment: A Fundamental Building Block for Tackling Chronic Disease*, to push this view. The paper defines the fuzzy concept of empowerment, describes how it can be "operationalised," and argues that it's not just a nice thing to do but a cost effective intervention that can be implemented widely and should be at the heart of health system reform in poor as well as rich countries.

Patients with complex chronic disease consume the lion's share of health budgets, and a few run up spectacular bills. In a compelling essay in the *New Yorker* Atul Gawande brings the concept of empowerment to life by describing how doctors have been able to help individual "superutilizers" of services by recognising that it's essential to forge close ties with them and shape services around them ("The hot spotters," 24 Jan, www.newyorker.com/reporting/2011/01/24/110124fa_fact_gawande).

Rushika Fernandopulle, a primary care physician in New Jersey, is one of the "pioneers" whose work Gawande cites. He is among a growing cadre of health professionals urging for root and branch reform of self serving paternalistic health systems that frustrate patients and doctors alike.

“We mostly deliver care the wrong way,” he says. “It’s doctor led, episodic, reactive, and [in the US] obscenely expensive. We are good at managing single diseases such as coronary artery disease but poor with the comorbid conditions such as obesity and depression, which are killing us.”

His practices have replaced fee for service payments with per capita charges; provided lay health coaches for patients with chronic disease; and “totally changed the way IT systems are used.” The health coaches are selected for “attitude,” not pre-existing knowledge, and have a background that chimes with the patients. They build close, long term, supportive personal relationships with patients (rather than dragoon them to comply with doctors’ orders), to promote their confidence and skill to self manage disease.

Patients have full online access to their medical records and relevant information, organise their own blood tests, feed in test results, schedule their own surgery visits, and let the practice know how they are getting on. The primary care team keeps a daily vigil on the data and the information that patients feed in; check whether prescriptions are collected, appointments kept, and unscheduled visits to secondary care made; and springs into action at the first sign of trouble. It’s a vision that most patients

with chronic disease, and those who care for them, can only dream of.

The World Health Organization sees patients’ growing interest in self management as a positive development and has flagged up the scope for new technologies to support it. The regional director of WHO’s European region, Zsuzsanna Jakab, refers to “increasing involvement in decision making of patients and citizens, who are no longer passive but, thanks to information technology, are more empowered than ever before to take more responsibility for their health in a different relationship with the health system.”

A new book, *Engaging Patients in Healthcare*, by Angela Coulter, director of global initiatives at the Foundation for Informed Medical Decision Making (www.informedmedicaldecisions.org), provides comprehensive guidance on how to promote self care. Its message echoes the one being sent out by the George Institute: patients in all countries can play a part in containing the burden of chronic disease—if given the chance.

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