

Care for chronic diseases

The efficacy of coordinated and patient centred care is established, but now is the time to test its effectiveness

See pp 854, 914,
925, 961

This is the third in the *BMJ*'s series of theme issues on managing chronic diseases. This focus reflects the increasing demands on practitioners and health systems around the globe posed by mounting numbers of chronically ill patients.¹ The term "chronic disease" usually connotes the prevalent chronic degenerative diseases such as diabetes, coronary artery disease, hypertension, and chronic obstructive pulmonary disease. But papers in the three theme issues argue that a much broader array of health problems generate similar needs for patients and similar challenges for health services—these include diseases such as chronic uveitis, gastro-oesophageal reflux disease, multiple sclerosis, depression, and osteoporosis.

Despite the clinical differences across these chronic conditions, each illness confronts patients and their families with the same spectrum of needs: to alter their behaviour; to deal with the social and emotional impacts of symptoms, disabilities, and approaching death; to take medicines; and to interact with medical care over time. In return, healthcare must ensure that patients receive the best treatment regimens to control disease and mitigate symptoms, as well as the information and support needed effectively to self manage their health and, in many instances, their death. Evidence shows that we are not doing very well, and that the fault lies less in ourselves and more in our systems of care.²

All three *BMJ* issues have presented or reviewed evidence showing that changes to the organisation and delivery of care can improve the quality of care and certain outcomes of chronic disease. The most successful interventions are complex and have many components. Their aims include increasing clinical expertise and decision support; improving patients' self management; increasing the effectiveness of practice teams and their interactions with patients; and having more accessible and useful clinical information (p 925).^{3,4} Such changes can reduce unwarranted variations in care (p 961),⁵ encourage patients to engage and stay with care programmes, and encourage more appropriate patient behaviour and decision making.⁶ In an editorial in the second *BMJ* issue on managing chronic disease, one of us (EHW) expressed the hope that by the third issue more widespread dissemination of these changes would be seen in practice.⁷

That hope seems to have been overly optimistic. Although research has shown the efficacy of these promising interventions, the effectiveness—the benefit in real clinical practice—has only begun to be tested. Will system changes tested for one disease be readily adaptable to other illnesses, to much younger patients, or to the many older ones with multiple chronic conditions? Will changes that improve healthcare delivery in Europe and the United Kingdom also work in less developed countries—for example, for AIDS care (pp 854 and 914)?^{8,9} We can't answer these questions yet, because we need further evidence that a common set of practice enhancements and systems will meet the needs of patients with one or more chronic conditions, wherever they live.

Furthermore, although the commonest chronic illnesses last for decades, most tested interventions for improving self management—an essential component of quality care for chronic illness—have been of relatively short duration and delivered outside usual medical practice. A recent meta-analysis of self management programmes for diabetes found that many succeeded in lowering serum concentrations of glycosylated haemoglobin, but their benefits diminished over the ensuing 6-12 months.¹⁰ How can the effect be sustained? Collaborative counselling and problem solving provided by primary care teams, as recommended or tested in these theme issues,⁶ may maintain and extend the benefits of these programmes over time, but this important hypothesis needs further study.

Meanwhile, the ideal drug treatment for most chronic illnesses gets more complicated every day, as trials of new agents and more complex regimens show both benefits and harms. Evidence based care for diabetes, heart failure, coronary artery disease, AIDS, and other chronic conditions now includes more complex drug regimens and the associated risks of adverse effects and potential interactions. Yet very few drug trials include patients with multiple chronic diseases, leaving an important gap in the evidence. Effective and safe chronic illness care will assure that practice teams prescribing and managing drug therapy have adequate knowledge and experience with these more complex drug regimens. This may entail the more active involvement of specialists with primary care teams.

So, there is much more to do. We hope that the evidence collected in these three special issues of the *BMJ* will provide a solid foundation on which to build. They

have, at least, uncovered a new generation of research questions needing urgent study. Such evidence, and the growing burden of chronic diseases, particularly in the world's poorest regions, should make researchers, funders, and policy makers think a lot harder about testing better, more effective, and more relevant ways to deliver care.

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The easiest way to find the two previous BMJ theme issues on managing chronic diseases is by going to bmj.com/collections/specials.shtml. They were published on 27 October 2001 and 26 February 2000.

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Managing chronic diseases in less developed countries

Healthy teamworking and patient partnership are just as important as adequate funding

Throughout the world, chronic diseases—including non-communicable diseases, long term mental disorders, and persistent communicable diseases such as tuberculosis and HIV/AIDS—present a huge challenge to health. As part of the response to this challenge, the World Health Organization has conducted a two year review of healthcare models and best practices from around the world and has recently reported on this work. The report, *Innovative Care for Chronic Conditions: Building Blocks for Action*, provides a comprehensive conceptual framework for the prevention and management of long term illnesses in poorly resourced settings.¹ The most fundamental issue highlighted by the report is the pressing need to shift away from an acute, reactive, and episodic model of care.

Instead, health care should facilitate an ongoing relationship between provider and patient and help patients to make full use of their own and their community's resources for health.² The focus has to be on the person in his or her own context, not simply on the disorder. Partnership between patient and provider is not just a resource for understanding health problems; it is the basis for prevention and intervention.³ Inattention to the interpersonal aspects of care has serious potential consequences. Patients accustomed to inadequate care may become resentful or respond with passive acceptance of the situation—often seeing it simply as a further burden of poverty and social alienation. Both responses will hamper active participation in an ongoing programme of health care.

How can we translate these important concepts into practice in health care, particularly in developing countries? At the heart of the challenge for policy makers is the reality that healthcare systems will never

have enough resources to meet all legitimate needs. Few providers, even in the best resourced settings, can say comfortably that they have done everything they conceivably could for all their patients. A paper in this week's *BMJ* by Rundall and others (p 958) bears this out by showing that even the leading healthcare providers in the United States find it hard to deliver really comprehensive care for people with chronic diseases.⁴

The term "resources" does not simply mean money: just as importantly, it also refers to the people who provide care and, in turn, the people who support and manage them. Providers who are overwhelmed by demand commonly defend themselves; getting into a vicious cycle in which they retreat from patients, patient demand increases, and providers have to withdraw further. All too often we hear criticisms such as, "If only they'd attend and listen to patients in the first place, patients wouldn't need to keep coming back and filling up the waiting rooms." It is easy to attribute such withdrawal to lack of expertise or even to moral failings, but, if health care in poorly resourced contexts is to succeed, the human need to reduce the anxiety associated with overload needs to be taken seriously, with staff receiving the right support.⁵

This dynamic presents important challenges to healthcare teams, particularly in developing countries. Where resources are scarce and epidemics such as tuberculosis and HIV infection are rife, managers may see providers only as pairs of hands. This gives those providers little scope to view patients as actors in their own lives or to build ongoing partnerships with them. Managers may, understandably, focus far more on the technical aspects of controlling epidemics than on supporting or caring for staff. The paradox is, of course, that continuing care delivered by a well

Education and debate
p 958

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