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Palliative care in chronic illness

We need to move from prognostic paralysis to active total care

Citation for published version:

Murray, SA, Boyd, K & Sheikh, A 2005, 'Palliative care in chronic illness: We need to move from prognostic paralysis to active total care', *British Medical Journal (BMJ)*, vol. 330, no. 7492, pp. 611-612.
<https://doi.org/10.1136/bmj.330.7492.611>

Digital Object Identifier (DOI):

[10.1136/bmj.330.7492.611](https://doi.org/10.1136/bmj.330.7492.611)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

British Medical Journal (BMJ)

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many years' effort by health services in rural areas, only 5.4% of people with hypertension receive drug treatment and only 0.9% have their blood pressure effectively controlled.⁷⁻¹¹

Research evidence on the biological efficacy of these drugs is often universally generalisable. Guidelines are, however, value laden, have cost implications, and are not universally applicable; thus those developed for one population may not suit another. As well as the thresholds for initiating treatment, factors such as treatment targets, competing priorities for drugs, diagnostic testing, and frequency of follow-up all have cost implications. The treatment target is the level of blood pressure or cholesterol to achieve through treatment—the lower the target the more resources are required to achieve it. China should probably consider targets that differ from those for Western populations.

Locally tailored treatment guidelines could further improve cost efficiency. For instance, antihypertensive drugs might be given precedence in China, particularly in the rural areas, over cholesterol lowering drugs

because they are cheaper and also reduce the incidence of stroke. Stroke is common in China, and in some areas it is the leading cause of death. Each year 1.3 million people have a first stroke, four times the incidence of acute myocardial infarction.¹²

Given national differences in epidemiology, local needs, and affordability, developing countries such as China need to tailor their national policies for managing chronic conditions. If policies for other populations are used, adapting, rather than simply adopting, will bring greater benefits to patients.

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Competing interests: None declared.

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Palliative care in chronic illness

We need to move from prognostic paralysis to active total care

Health, social, and palliative care services are continuing to fail many people with progressive chronic illnesses in whom death may be approaching, reflecting a failure to think proactively and holistically about their care.¹ Such people could, however, readily be identified by clinicians asking themselves, "Would I be surprised if my patient were to die in the next 12 months?" For patients in whom the answer is no, delivery of patient centred active treatment and supportive care are needed.

Prognostic paralysis has been described, whereby clinicians of patients with uncertain illness trajectories prevaricate when considering end of life issues.² For example, one general practitioner graphically summarised the feelings many experience in caring for people with terminal heart failure: "You're paddling downstream to Niagara." Another felt reduced to clinical tasks: "I feel impotent, merely a blood leech and monitor."³ End stage chronic obstructive pulmonary disease is another example where patients seldom receive holistic care appropriate to their needs.⁴ Decision analysis in end stage renal failure should include the option of palliative care.⁵ Similarly, management of diabetes at the end of

life may need to be altered to reflect different, more appropriate goals.⁶ To help overcome prognostic paralysis, quality improvement teams in the United States suggest that, rather than target patients who will die in the next six months, we should focus on those who "reasonably might die."⁷ In the United Kingdom at least, opportunities now exist to initiate such an approach.

The new general practitioner contract has resulted in the establishment of many patients' registers, such as those for chronic obstructive pulmonary disease, ischaemic heart disease, and cardiac failure.⁸ Practices are now reimbursed for doing regular assessments and investigations, offering regular opportunities to identify those who may be entering the last months of life. When establishing these registers and reviewing those on them clinicians should routinely ask the question of anticipated prognosis.

Community nurses are playing a larger part in caring for people with chronic illnesses. Practice nurses reviewing people annually, district nurses caring for housebound patients, and health visitors proactively visiting the elderly could all periodically ask themselves this question as a trigger to adopting a holistic

palliative care approach. Palliative care in the community can thus become more extensive and proactive.⁹

How might patients and professionals feel about a more proactive approach to palliative care? The acceptance of palliation requires a joint signing up by professionals, the patient, the family, or other carers. Early recognition is necessary, but not sufficient, for effective care. Most people with progressive chronic illnesses have already brushed with death and have competing narratives in their minds. On the one hand they hope that their condition will not deteriorate, and on the other they acknowledge that death is inevitable.¹ Greater awareness of these conflicting narratives should make it easier for professionals to combine active treatment and a supportive approach. People with disabling, progressive illnesses expect active care, but they also seek comfort, control, and dignity. The barriers to effective communication about emotional and end of life issues are well recognised. Doctors' concerns include causing distress, damaging hope, and having time for such discussions. Patients and families have equal problems.¹⁰ An individual approach to sharing information in the context of a good professional-patient relationship is key.¹¹ Some opening questions that might help professionals start to explore these issues with patients who wish to do so are given in the box.

Estimating prognosis is an inexact science,¹² but prognostic uncertainty should not prevent us talking

Adopting patient centred supportive care: possible questions

- What's the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- If things got worse, where would you like to be cared for?

with our patients about this issue, as a noteworthy number will die suddenly. We must not inadvertently fall into the trap of prognostic paralysis. So when we are next monitoring prognostic indicators and observe an irreversible decline, why not simply ask ourselves: "Would I be surprised if my patient were to die in the next 12 months?" And if the answer is no, we need to give the patient and his or her family an opportunity to plan for a good death, instead of just monitoring a downward set of physical variables until death.

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Conflict of interest: None declared.

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Nurses as leaders in chronic care

Their role is pivotal in improving care for chronic diseases

The chronic care model is widely accepted as a standard for improving care for people with chronic conditions.¹ In the United States, projects to put the chronic care model into practice often centre around doctors. Yet the healthcare literature and the experience of many efforts to improve chronic care indicate that nurses, not doctors, are the key to implementing the chronic care model in a patient centred care team. By nature of their education and role, nurses are in a position to champion transformation of chronic care. In many nations, but not in the United States, nurses have been taking this central role for decades.^{w1}

The essence of the chronic care model is the interaction between an informed, activated patient and a prepared, proactive practice team.^{w2} Indeed, such a team is nearly always needed to enable patients to become

adequately informed and activated. What is the record of doctors in informing and activating patients?

A study of family physicians in the United States found that patients making an initial statement of their problem were interrupted by the doctor after an average of 23 seconds.² Half of patients finish an office visit not understanding what they were told by the doctor.³ The commonest reason for patients not taking their medicines as prescribed is poor communication from doctor to patient.^{w3} In a study of treatment decisions in over 1000 audiotaped outpatient visits to doctors, the patient was not involved in the decisions 91% of the time.⁴ Poorly informed passive patients are less likely to

 References w1-w10 and details of nurse led projects are on bmj.com