

EDITORIALS

Beyond diagnosis: rising to the multimorbidity challenge

Urgently needs radical shifts in research, evidence based guidance, and healthcare

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In January 2012 the Institute of Medicine in the United States published the report of a consensus study on living well with chronic illness. The report made 17 recommendations for public health approaches to chronic disease prevention, surveillance, data gathering, and chronic disease management programmes that would help improve quality of life and functioning and reduce disability.¹ Although the report makes some interesting recommendations (box 1), particularly about research in chronic disease, and displays a welcome shift in emphasis to “living well” rather than reducing mortality, it falls short of making the necessary paradigm shift from a disease based model to one that focuses on care for patients. This shift in thinking is urgently needed to provide good care for patients with multiple comorbidities.

The medical profession faces substantial challenges in caring for patients with chronic comorbidity well. The taxonomy of diseases with which we work has accrued piecemeal over the centuries. Some diagnostic labels have proved immensely useful, others much less so.² With the development of numerous biomarkers for disease, diagnosis has become increasingly detached from symptoms, to the detriment of those with chronic illness.

Comorbidity is seen in patients of all ages. Half of people over 65 years of age have at least three coexisting chronic conditions. One in five has five or more. Although the proportion of patients who have comorbidities increases in older age groups, the largest numbers of patients with multiple comorbidities are under 65.³ More than half of patients attending primary care in the UK have multiple chronic conditions, and such patients take up an even greater proportion of consultations.⁴ In a study of Medicare beneficiaries, the proportion of patients with more than five treated conditions increased from 31% to 50% from 1987 to 2002.⁵ The age adjusted prevalences for hyperlipidaemia, osteoporosis, and mental disorders increased even more steeply. It is also worth noting that the diagnoses that are most rapidly on the rise are those for which new drug treatments are available.

In recent years the single disease model has become an end in itself as disease management frameworks and targets for single conditions have become embedded in evidence based guidance and care pathways. Focus has shifted from patients and their experience of diseases to measuring parameters of the diseases themselves. Although evidence based models of single diseases in isolation work well for patients with one disease, they can lead to “siloeing” of care for people with multiple conditions, and this can result in chaotic care. One study found that applying individual disease guidelines to a patient with five chronic conditions would result in the prescription of 19 doses of 12 different drugs, taken at five time points during the day, and carrying the risk of 10 attendant interactions or adverse events.⁶ Care that is “measurably better” may be meaningfully worse and a nightmare for the patient.

Adverse events related to drugs are among the top five causes of death in US hospitals, and rates of hospital admission for this indication in people over 65 are estimated at 17%. This is an important, expensive, and iatrogenic source of morbidity in people with multiple chronic conditions that is invisible in recommendations for care in chronic illness. Research, guidelines, and models of care seldom support the complex and difficult decisions about which treatments should not be given or when to stop treatment. The use of guidelines as standards enshrines polypharmacy and therapeutic positivism because this approach measures and evaluates quality of care by counting how often treatments are given, rather than not given. Largely ignored are the problems of adverse drug effects, and the value of a patient centred approach to care. However, prioritising these are the key to reducing morbidity and mortality in patients with chronic comorbidity and to tackling a financial burden that is crippling health systems.^{7 8 9}

Chronic illness is characterised by its variability.^{10 11} Recommendations in guidelines are often based on the average response in study populations that are usually selected to be free of comorbidity and polypharmacy. Applying such evidence

Box 1 Summary of the Institute of Medicine report, *Living Well with Chronic Illness*¹

This detailed literature review uses exemplar conditions including arthritis, survivorship after cancer, chronic pain, dementia, depression, type 2 diabetes, post-traumatic disabling conditions, schizophrenia, and vision and hearing loss to give broad recommendations. Its main recommendations are:

- Resources should be used wisely in the current financially difficult environment. The Centers for Disease Control and Prevention should focus on a select range of diseases
- Research and programme evaluation should provide better scientific and economic evidence on the effectiveness of chronic disease programmes and models of care
- Focus on quality of life outcome measures for research and programme evaluation and on interventions that reduce the disparity in healthcare that leads to inequity in outcomes
- Take a more coordinated approach to meeting both health and social needs that facilitates collaboration between population health, clinical, and non-health services, employers, and community organisations
- Collect better data for surveillance of chronic illnesses as well as the effect of interventions and models of care on patient reported quality of life outcomes. The report makes specific recommendations for the use and sharing of information from electronic medical records on coexisting chronic illnesses
- Engage in research on the effects of preventive and lifestyle interventions on both quality of life for people with existing illness and primary prevention. Find ways to implement prevention effectively

to the treatment of those with comorbidity who are taking a variety of drugs reduces benefit to an unknown extent and increases the potential for harm. The evidence base for the effect of treatments in the context of comorbidity is poor and does not account for variability in the genesis, expression, and progression of illness; the interaction of illnesses; the physiological damage caused by the stress from life events; and the impact of biopsychosocial interventions.¹⁰⁻¹² There are few studies in the very elderly. In this group, explanatory models and interventions extrapolated from studies of younger patients do not necessarily work or match patients' priorities for care.¹³⁻¹⁵

Healthcare systems that are underpinned by strong generalist primary care produce better health outcomes for patients with chronic illness at lower cost and with less health inequality than those that are not.⁹ Specialists provide better condition specific care measured by guideline adherence for patients with single conditions, but generalists provide better care for those with multiple conditions.⁹ This may be because generalist care is pragmatic and iterative, and it is based around the symptoms, values, and priorities of the particular person rather than particular diseases. Generalist care has the potential for "quarternary prevention"—that is, protecting patients from gratuitous diagnostic labels, tests, and treatments that offer no benefit with regard to mortality and morbidity and are driven by misplaced goodwill or commercial interests.¹² However, all these attributes are being rapidly eroded in the face of payment by results and a system that evaluates the quality of care and of doctors on the basis of siloed adherence to evidence based guidelines for single diseases. This move carries the potential to disempower doctors and patients and prevent them from using their observation of individual responses and needs.

There is a pressing need to reverse the current trend towards management of individual diseases in silos so that care of patients with chronic comorbid illness is much more closely driven by their particular symptoms, needs, and treatment effects and their own priorities for care. An improvement in health status must be seen not as an end in itself but as the means to fulfilment and possibility in the life of the patient. Furthermore, healthcare systems need to start to value and provide adequate support for the kind of iterative generalist care that focuses more on the person than on the disease entity and the necessary variation this entails. This would place equal value on the art of "not doing"—making complex decisions not to give treatments, not to order tests, and to stop current treatments when in the best interests of the patient.

To achieve this, uncomfortable shifts in research, evidence based guidance, and systems and funding of care are needed (box 2). While routinely collected data are useful for research, they

almost invariably comprise data linked to single diagnoses, and information from the real world testing of treatment effects and systems of care among huge numbers of patients with multiple illnesses remains largely invisible. Technologies such as electronic medical records that include patient input are potentially useful in dealing with these problems, but only if both their form and function go beyond diagnostic labels and make visible the patients' individual symptomatic pattern of comorbidity along with their identified priorities for care. If patients with chronic comorbidity are to get the best from medical care, there is an urgent need for these different ways of thinking—beyond diagnoses. In the words of William Osler: "It is more important to know what type of person has the disease than to know what type of disease the person has."

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Box 2 Summary points

The piecemeal rise of diagnostic labels and biomarkers for illness has led to diagnosis that is often detached from symptoms

Current single disease approaches to research and guidelines encourages siloing of care that can be harmful, complex, and time consuming for patients with chronic comorbidity, and burdensome for health systems

Research rarely investigates, and guidelines rarely support, complex and difficult decisions about when to stop or not give treatments

Care for patients with chronic comorbid illness must be more closely driven by patients' individual experience of illness and treatment effects, and their priorities for care

Shifts in the frameworks of research, guidance, and funding, in addition to changes in the values and technologies underpinning healthcare systems, are needed to ensure care that focuses on the person rather than management that focuses on diseases

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