

# We need minimally disruptive medicine

The burden of treatment for many people with complex, chronic, comorbidities reduces their capacity to collaborate in their care. **Carl May, Victor Montori, and Frances Mair** argue that to be effective, care must be less disruptive

Chronic disease is the great epidemic of our times, but the strategies we have developed to manage it have created a growing burden for patients. This treatment burden induces poor adherence, wasted resources, and poor outcomes. Against this background, we call for minimally disruptive medicine that seeks to tailor treatment regimens to the realities of the daily lives of patients. Such an approach could greatly improve the care and quality of life for patients.

## Non-adherence, culpability, and susceptibility

Poor adherence to medical advice and drug regimens is a global problem with a long history. Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources.<sup>1-3</sup>

The aetiology of non-adherence is complex, but individual culpability has been assumed to play an important part.<sup>4-5</sup> People with chronic (and other) illnesses who do not adhere to treatment generally say that they recognise that they ought to do otherwise but that they lack the capacity, skills, and understanding to do so. In one study, 45% of patients gave such reasons for intentionally not adhering to treatment for chronic illnesses.<sup>6</sup> Recent research on adherence has focused, therefore, on interventions. The aim of these interventions is twofold: to improve patient uptake of treatments by giving them tools to share in understanding the relevance and importance of certain behaviours and treatments; and to encourage them to “buy in” to those behaviours and enhance their ownership of therapeutic regimens. Much of the research has been done in the context of randomised controlled trials of treatments

for quite narrowly defined patient groups. Thus our understanding of adherence is of limited applicability to usual care.<sup>3-7-9</sup>

## Chronic illness and chronic workload

Studies that examine adherence often exclude two large groups of patients that health professionals encounter in real life: people who have diminished capacity to cope with therapeutic regimens because of cognitive impairment and people with multiple chronic comorbidities. Both groups often present complex social problems that are related to their illness and confound treatment.<sup>10</sup> Perhaps more than 60% of older people have multiple chronic conditions, representing an increasing proportion of people who need health care.<sup>11-12</sup>

The burden of chronic illness falls not only on health services but also on patients and carers, as the work of managing chronic disease increasingly shifts from the clinic to the home. They must cope with increasingly complex treatment regimens and work to normalise these in their daily lives (see example 1 in box).<sup>13</sup>

Other factors exacerbate this situation. Treatment burdens are often imposed on patients with little coordination between, or even within, clinics dealing with different conditions and little explicit recognition that treatment regimens are demanding in time and effort. In addition, evidence based guidelines provide disease specific guidance for doctors but often fail to acknowledge multiple morbidities as management



## Patient burden of health care

*Example 1*—A man being treated for heart failure in UK primary care rejected the offer to attend a specialist heart failure clinic to optimise management of his condition. He stated that in the previous two years he had made 54 visits to specialist clinics for consultant appointments, diagnostic tests, and treatment. The equivalent of one full day every two weeks was devoted to this work.

*Example 2*—In the US, a woman in her late 70s was under medical evaluation for possible placement in a nursing home because of “inability to care for herself.” Detailed questioning revealed that she was taking medications at 11 separate times during the day, which was very disruptive of her life, especially as some of these doses were linked to food ingestion. None of her doctors was aware of this behaviour. The pharmacist was able to consolidate and schedule the medicines around the woman’s activities into a three times daily administration. She continues to live independently.

*Example 3*—In the UK, a man in his late 70s with heart failure talked of the effort required to adhere to a complex drug regimen: “I’ve got a book and I note everything down. I note the time, the drug, and when I’ve taken it. When you are doing activities throughout the house or you are otherwise engaged you can quite easily forget to take them and sometimes you don’t really know whether you’ve taken them or not—that can happen, its surprising. So I make a point of noting down the drug I take and the time I take it and I tick it off. So if I think that I haven’t done it, I have a look and if I haven’t ticked it off and noted down I assume I haven’t taken it. You have to be careful, particularly with the warfarin. They are very keen on you maintaining your dose.”

*Example 4*—In the US, a primary care doctor referred a man in his 50s with type 2 diabetes and a raised glycated haemoglobin concentration to an endocrinologist after noting insufficient glycaemic control with maximum doses of metformin and glipizide. The endocrinologist added pioglitazone and maximised the dose with no response. Similar failure accompanied the use of exenatide. A year after starting to see the endocrinologist the patient’s HbA<sub>1c</sub> concentration was even higher. When the endocrinologist offered glargine insulin instead, the patient complained that the drugs were too expensive. A review of his pharmacy records indicated that the patient had never collected the prescriptions for pioglitazone or exenatide because of their cost.

problems. Fractured care means that such patients often receive care from several different clinicians, whose uncoordinated prescriptions and recommendations lead to polypharmacy, increased treatment costs, side effects, and unintended drug interactions. Patients are thus overwhelmed not just by the burden of illness, but by the ever present and expanding burden of treatment (see examples 2 and 3 in box).

The work of being a patient includes much more than drug management and self monitoring. It also includes organising doctors’ visits and laboratory tests. Patients may also need to take on the organisational work of passing basic information about their care between different healthcare providers and professionals. In some countries, they must also take on the contending demands of insurance and welfare agencies. This means that although intensifying treatment often seems the solution to the patient’s problems, it adds to them (see example 4). Advances in diagnosis and treatment thus have the paradoxical effect of adding incrementally to the work of being sick. Patients who cannot cope eventually experience iatrogenic outcomes and poorer quality of life, just as surely as do those who are affected by medical accidents or errors. Clinicians cannot respond adequately to this problem. They lack the tools to detect patients overwhelmed by the burdens of treatment, and they lack strategies to lift these burdens.

### Four principles for minimally disruptive medicine

We have highlighted two problems in the care of people with chronic conditions: non-adherence with treatment and uncoordinated and increasing workload. These problems have important connections. We propose that some non-adherence is structurally induced by the healthcare system.

Our diagnosis of the overburdened patient suggests that complex, chronic, comorbidities have their counterparts in problems of healthcare systems themselves.

Are there solutions to these structurally induced problems? Solving them will be a long haul. But we can make a start by applying four principles to guide health services design and clinical research questions.

*Establish the weight of burden*—Clinicians and researchers need reliable tools to identify overburdened patients and those with capacity problems, such as poor recall or comprehension of instructions or difficulties in administering their treatment. These tools must describe treatment burden across individuals requiring similar treatment, taking into account patient values and preferences as well as the effects of multiple comorbidity and social circumstances—asking, what is the effective yet least burdensome treatment programme for this person with this set of

conditions in this context? They would also describe treatment burden within the same individual over time. Healthcare providers also need reliable tools to understand so called non-adherence as a problem that can be structurally induced at a system level by their own beliefs, preferences, and behaviours.

*Encourage coordination in clinical practice*—The role of primary care doctors in managing chronic disease has been an important focus of policy debates on both sides of the Atlantic.<sup>14</sup> Primary care has traditionally sought to coordinate care for people with multiple morbidities. However, incentives have been used mainly to improve outcomes in specific diseases (such as asthma, diabetes) rather than to manage complexity and comorbidity. For example, the new general medical services contract in the UK offers incentives to meet key clinical targets for individual chronic diseases. Incentives should instead prioritise holistic approaches and improved coordination of care.<sup>15</sup>

*Acknowledge comorbidity in clinical evidence*—Incentives to improve disease specific outcomes rely on an evidence base that focuses on disease specific processes. The effects of complexity and comorbidity are systematically excluded from most practice guidelines.<sup>16</sup> Improved coordination of care depends on the improved coordination of clinical knowledge, and the development

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of robust techniques for translating this into clinical guidelines that deal explicitly with the problems of managing multiple chronic conditions. Even though the permutations of comor-

bidity are a problem, such guidelines could cover chronic conditions that commonly coexist, such as diabetes, coronary heart disease, heart failure, and chronic obstructive pulmonary disease.

*Prioritise from the patient perspective*—Patients have a role in improving the coordination of their care, and this extends beyond administrative work on behalf of a health provider. A core assumption of principles of patient autonomy and shared decision making, and a constant feature of research on experiences of sick people, is that they are able to make meaningful choices about the interactions between their illnesses and clinical interventions.<sup>17</sup> Since only patients and their caregivers can report on the burden of treatment, they should participate in deciding which conditions to tackle next and to what extent. Given the evidence for efficacy and the burden of treatment involved, an asymptomatic patient with diabetes, for example, may

prefer to approach lipid and blood pressure control before seeking to control glycaemia. Patient involvement must be a central part of disentangling individual and collective treatment burdens.

Together these principles may inform policy and practice that enhance clinical and cost effectiveness, and at the same time be easier, safer, and less costly for patients to enact in their own lives. They also offer an opportunity to reinvigorate and re-emphasise the importance of the generalist role of the primary care doctor at a time when—in the UK, at least—there is increased emphasis on disease specific targeting and much routine chronic disease surveillance and management is delegated to nurses or patients. The principles have important implications for the relation between research and practice. Here, health services research, the social sciences, clinical medicine, and the basic sciences of therapeutics can interact with each other in new ways. This is because solutions to the problems we identify need to address highly complex systems rather than individual pathological processes. In such a context, polypills—which are such contentious solutions to public health problems—become suitable approaches to complex comorbidities in clinical medicine. Such approaches have recently been shown to make important contributions to improved patient outcomes in the management of HIV and AIDS.<sup>18</sup>

### Conclusion

We need to think more about the burdens of treatment. These are different from the burdens of illness. This becomes more urgent in

the light of the policy emphasis on self care and what we know about its effects.<sup>19</sup> More fundamentally, thinking seriously about the burden of treatment may help us begin to think about minimally disruptive medicine—forms of effective treatment and service provision that are designed to reduce the burden of treatment on their users.

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### CASE REPORT

#### Orthopnoea in a young woman

- 1 Respiratory muscle weakness causing nocturnal hypoventilation and cor pulmonale. Overnight oximetry showed precipitous desaturation associated with reflex tachycardia on lying flat, suggestive of respiratory muscle weakness. This is supported by the history of orthopnoea and previous episode of type 2 respiratory failure.
- 2 First line investigations are: lung function tests (spirometry, lung volumes, and gas transfer); lying, sitting, and standing spirometry; maximal inspiratory mouth pressures and sniff nasal inspiratory pressures. Other investigations include measurement of transdiaphragmatic pressure and phrenic nerve magnetic stimulation if available.
- 3 Possible causes are: neural abnormalities (Guillain-Barré syndrome, trauma, mediastinal malignancies, herpes zoster, motor neurone disease, vasculitis, hereditary sensorimotor polyneuropathy, critical illness polyneuropathy, alcoholism, diabetes); disorders of the neuromuscular junction (toxins, drugs, myasthenia gravis); and abnormalities of muscle tissue (muscular dystrophies, myopathies, acid maltase deficiency, hypothyroidism, systemic lupus erythematosus, mechanical ventilation induced diaphragmatic dysfunction).

### PICTURE QUIZ

#### An unusual case of haemorrhagic stroke

- 1 The head computed tomogram shows a subarachnoid haemorrhage in the left sylvian fissure and overlying convexity.
- 2 The most common causes of non-traumatic subarachnoid haemorrhage are ruptured intracranial aneurysms and arteriovenous malformations.
- 3 A filling defect throughout the left transverse and sigmoid sinuses can be seen on the digital subtraction angiogram, which is suggestive of venous sinus thrombosis.
- 4 The treatment for venous sinus thrombosis is anticoagulation with heparin and subsequently warfarin.