

The art of medicine

Rethinking personalised medicine

Watching my own mother age crippled by chronic diseases has been profoundly distressing. But living in India, a country that has, arguably, one of the most unjust health-care systems in the world, makes the experience immeasurably more difficult. Indians have two, diametrically opposite, choices for health care when afflicted by a chronic disease. Barring islands of excellence, both choices offer poor quality care, albeit for different reasons. One choice is a dysfunctional and fragmented public health-care system with limited medicines, disinterested health-care staff, and inconvenient opening hours. This forces many people to seek help from the alternative: a rapacious, corrupt, unregulated, private health system.

The consequences of this appalling situation do not only lead to a poorer quality of life but are also financially catastrophic. It is heart-breaking enough to see my mother endure her health problems, but even worse to see her argue that she wants to stop dialysis because it is costing too much and eating into the savings she hoped to gift to my sisters. And this is a mother who lives in an upper-middle-class family with considerable assets at one time, assets which have gradually been eroded by the mounting medical bills that both my parents have incurred as they age. The predicament faced by my fellow citizens who live in poverty is even worse: as my mother's home-care helper once remarked, anyone in her village with such complex health problems would have died a long time ago. My mother's recent admissions to a private hospital give a snapshot of what happened to her.

During her admissions, I saw my mother consult almost every specialty that medicine has invented. A neurologist for her headache, a dermatologist for her skin rash, a nephrologist for her kidney failure, a gastroenterologist for her diarrhoea, and the list goes on. Each visit, which typically lasted a few minutes, was priced handsomely. She also underwent virtually every investigation that medicine (or the industry, to be precise) had invented. An MRI scan for her brain, an abdominal ultrasound for her kidneys, a colonoscopy for her gut, and the usual (and some unusual) blood investigations. None, of course, showed anything sinister or not previously known. Moreover, she was prescribed 14 drugs. Apart from the cost, I was worried because she had had at least three hospital admissions in the past couple of years precipitated by medication side-effects.

Now, it must be admitted that my mother's physicians are all respected professionals, people of integrity and with impeccably warm manners, and they might argue that my mother received the best care in the spirit of personalised medicine, a much touted approach designed to tailor medical treatments to "the individual characteristics,

needs, and preferences of a patient during all stages of care". I fear they are wrong.

My mother loves her doctors, but hates the care she receives, not least the regular admissions to hospitals and the expense. In my view, for all practical purposes, her care is only personalised for the benefit of her physicians: each deals with a tiny part of her body and leaves the rest to other specialists. There is no one to coordinate her care, perhaps the single most important intervention in the management of chronic diseases. There is no one to guide her to implement the essential behavioural interventions that can slow the progression of her diseases; few doctors seem to have any interest in spending time doing such low-tech stuff. There is no one to follow her up at home to proactively review her condition with the goal of maintaining good progress and preventing future hospital admissions. If this is personalised medicine, then the people of India are likely to drown in an ocean of medical debt, enriching corporate hospitals, private physicians, and the pharmaceutical and medical device industry. Indeed, my experience of the private medical system over the past 10 years of my mother's illness has made me see why some refer to it as the "medical industrial complex".

Many economists have worked hard to estimate the trillions of dollars that chronic diseases will cost the global economy, and while these reports rightly call for investments in prevention, I am always surprised at how the resurgent costs of a rampant medical industry are not challenged; instead, the onus is on government to increase spending to pay for these costs, typically through some form of insurance. Of course, this will only worsen the problem since insurance (at least the Indian variants) is mostly paid out for hospital admissions and inpatient procedures. The substantial, and growing, body of evidence that indicates how care for patients with chronic diseases should be provided, leading to lower costs, higher patient satisfaction, and, more importantly, better outcomes, seems to be ignored. Although one may not be surprised if the private medical sector is not enthused by an approach that promises lower costs of care, it remains a mystery why the organisations which are paying for this care, such as insurance companies and governments, ignore this evidence.

What does the evidence show? Quite simply, that the key to personalised medicine for chronic diseases is to put the patient at the heart of the treatment programme. This will require reconsidering four major assumptions that underlie personalised medicine: what comprises the intervention; who provides it; where is it provided; and who is the target of the intervention. Public health approaches to chronic diseases have innovative approaches for re-engineering each of these assumptions.

For many chronic diseases, the approach favoured by current practitioners of personalised medicine is to treat the specific diagnostic syndrome, which leads to fragmentation of the patient's problems into the domains of the myriad organ-based specialties, with the consequence that the patient herself is lost from the picture. First, there is a need to re-engineer interventions so that they are trans-diagnostic and address patient-defined outcomes that are typically related to impairments in daily living. For many chronic diseases, this usually requires assistance with modifying lifestyles and behaviours, improving adherence to medicines, and environmental adaptations.

This approach leads me to the second innovation: to re-engineer our notion of health-care delivery platforms. These platforms are currently designed to suit the specialist; they require that the patient, often an older person who is not independently mobile, goes to the hospital repeatedly for a consultation which usually lasts a few minutes. The ideal delivery platform is the person's own home, especially for non-urgent care, not only because it is more convenient but also because it is arguably the best place for patients to learn how to change their behaviours and modify environments.

No doubt, this approach is unlikely to be acceptable to specialist physicians, but the evidence suggests that this barrier could be addressed by a third innovation: to rethink our idea of who provides the care. The front-line agent of health-care delivery is a non-physician health worker whose core skills are in the psychosocial and nursing realms. Such a worker could also act as the care manager, ensuring coordination of the diverse health-care needs typical of many patients with chronic diseases. Another key human resource is the good old-fashioned family doctor—a primary care physician who is competent to provide rational care for most medical conditions and whose greatest skill is knowing exactly when to and, even more importantly, when not to refer to a more specialised provider.

Finally, chronic diseases almost always affect others who live with the patient; often, they too, as a consequence of advanced age, shared environments, and the stress of caring for a sick person, are affected by a chronic disease. My father has been my mother's primary caregiver, but has himself struggled for over a decade with mobility problems and back pain. Thus, the target of the intervention needs to be re-engineered so that the focus can shift from the individual to the family in recognition not only of the family's role as the primary provider of care, but also that chronic diseases tend to cluster in families.

These four structural modifications are what I believe are needed to transform our vision of personalised medicine for chronic diseases, and in doing so achieve both an improvement in the outcomes for patients and their families, as well as a reduction in costs. In practical terms, it means one major health-system adaptation: the deployment of community-based workers linked to a primary care



Photo Faraz Dhanani Patel

physician who has responsibility for the care of a defined number of households. This should be the front-line chronic disease team for India, not the plethora of specialists in the super-specialty hospitals mushrooming around the country today. Although the push towards universal health coverage to expand access to care for chronic diseases through a regulated and integrated health-care system is essential, it is not enough since following the existing model of care will bankrupt the nation. We, in particular my fellow physicians, must work actively to bridge the abyss between clinical medicine and the robust evidence base derived from public health. This evidence points to the benefits of a collaborative, coordinated, continuing, and community-oriented model of care. These are the guiding principles that must be fully integrated in clinical practice. Beyond the economic arguments, these changes are needed because the millions of people affected by chronic diseases deserve a truly personalised solution to their health problems.

In recent months, I find my mother in much brighter spirits than I have seen her for a long time. She tells me that she has now invited a family doctor to start visiting her at home regularly, to “take over her care”, and among the first things he did was to cut her medicines by half. She is elated. She also told my father and me that she never wanted to return to hospital, under any circumstances, and understood fully the potential implications of this decision on her life expectancy. She asserted, in an enviably calm way, that she had lived a full life and wanted to die at home, by the side of the man she had spent 60 years with. I could not but agree.

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Further reading

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