

Healthcare jewels from the caves of suffering

Mark Metherell

A paradox of modern healthcare is that despite the huge strides in health and behavioural science, the value of patient experience and leadership often remains under-recognised and underused.

In his new ebook, English author and patient advocate David Gilbert shows us just how much healthcare is missing out in failing to value what he calls the “wisdom and insight forged in the caves of suffering”.

Gilbert produces many jewels from his cave revealing the glittering fortune of improved outcomes awaiting patients and practitioners who recognise and deploy the treasure of patient experience.

The full title of Gilbert’s book, *The Patient Leadership Triangle: A practical engagement model for transforming healthcare*, gives us a sense of the structural platforms required to make the most of the knowledge patients can bring to the health system.

Gilbert has himself lived through significant ill-health and fought through bracing managerial battles to elevate the role of the patient in system design and influence to the extent that he now carries the title of ‘Patient Director’ in his Sussex musculoskeletal centre.

“We need to stop seeing ‘patients’ as only weak...we are strong by dint of what we have had to face...As a society we have so debased illness as weakness or as a problem to be fixed --- we have also inadvertently turned patients away from their agency.”

The Patient Leadership Triangle represents the three roles of and relationships between the Patient Director, who is at executive level, the Patient and Carer Forum, at corporate governance level, and Patient and Carer Partners at design delivery and team governance level.

Given the different funding and administrative systems in England’s NHS, an exact replica of that structure may seem unlikely in Australia. It is however highly relevant for us as a guide to effective patient involvement.

“True patient partnership has deep implications for transparency, governance and accountability.”

This is a book notable for its no-nonsense, pithy advice. He writes of the “classic leadership dilemma”. “How was I to straddle the role of being an insider (the helper) and of wanting to shift culture to one that was more ‘patient-centred’ (the critic)?”

He struggled in the early years of the position which he said made him more empathetic to staff cultures and wellbeing. “There are many who now confide in me because I have been open about my mental health problems.”

The Patient and Carer Partners were more than storytellers, not recounting their own experiences so much as being ongoing partners, able to reframe problems, generate solutions, model collaborative leadership and shift dynamics.

An example was a patient suggestion to reduce the high number of cancelled appointments by giving patients more say over appointment times. Patient and carer partners have been involved in major improvements, redesigning pain services, developing self-management programs, designing apps and even sitting in on recruitment panels including for the next managing director.

That two clinicians approached Patient and Carer Partners to seek help in assessing the quality of shared decision-making showed how far they had come as trusted equals in improvement and delivery of services.

The Patient and Carer Forum, overseeing activities at a corporate and governance level, has been involved in improving communications in areas such as hospital signage, website redesign and responding to patient feedback on information issues.

The forum works to ensure patient insights are taken account of, reporting patient comments to clinical leaders.

Gilbert says one of his key objections to traditional forms of engagement is that it is professionals “who filter data about patients through their own lenses and decide what can be done without patients in the room”. The right outcome may seem obvious, but success takes time and determination. As he says: “Simple is not easy.”

The patient movement is however having some success at Gilbert’s centre. Last year 98 per cent of the patients accessing the service felt involved in a shared decision --- a significant rise in recent times.

Shared decision making has produced financial savings including a seven per cent reduction in referrals and reduced secondary care surgery, generating a savings of about \$14 million on projected expenditure over three years.

In an epilogue to the book, Gilbert acknowledges that the coronavirus pandemic has brought crisis-driven management changes to health and social care bereft of patient, user, carer and citizen input.

But he says the optimist in him sees countervailing trends such as community connectedness and changing patient-professional interactions, partly as a result of the shift to virtual consultations in primary care.

“This virus might serve to amplify our common vulnerability, fallibility and suffering; but also the jewels of wisdom and insight that are dug from the caves of suffering. Lockdown can unlock our human potential.”

The Patient Leadership Triangle: A Practical Engagement Model for Transforming Healthcare is published in Australia by Bang the Table Pty Ltd, at bangthetable.com.

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