Partnering with patients

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Last month we published a plea from Dave deBronkart (also known as e-Patient Dave) to “let patients help.” As a survivor of stage IV, grade 4 renal cell carcinoma, he described how the online patient community helped save his life (BMJ 2013;346:f1990). His aim is nothing less than to revolutionise the relationship between patients and healthcare providers. “Please,” he wrote, “let patients help improve healthcare. Let patients help steer our decisions, strategic and practical. Let patients help define what value in medicine is.”

This week we hear from another e-Patient, Kelly Young, who tells us why she became “a rheumatoid arthritis warrior” (doi:10.1136/bmj.f2901). Her blog, rawarrior.com, was born of the realisation that her doctors were stumped and that she needed to take responsibility for understanding her condition and deciding about her care. The blog now reaches nearly 2% of all patients with rheumatoid disease in the United States and, according to Young, is changing the way doctors as well as patients think about the disease.

The language of revolution and war may seem excessively violent, but it reflects the sense that even internet empowered patients feel they must fight to be heard, to get access to information, and to have their say in treatment decisions.

The BMJ is a journal for doctors. Over the years we have resisted the temptation to widen our sights to include patients among our target readership, although we know that many of our online readers are patients and members of the public. Despite its name, our series of Patient Journey articles is not designed for patients. As recently summarised by the BMJ’s patient editor, Peter Lapsley (BMJ 2013;346:f1988), these articles aim to give our medical readers new insights into patients’ experiences of illness and treatment in order to improve care.

But Young, deBronkart, and others like them are looking for something more than simply more empathetic doctors. They want partnership on an equal footing. And it’s this shift that the BMJ now wants to champion, working with colleagues at the Mayo clinic and others. As several of us ask in an Editorial this week, how better to improve care than to enlist the help of those whom the system is intended to serve?

Achieving such a partnership is a challenge. Years of paternalism have left doctors and patients unprepared for a different type of interaction. Time and other pressures may seem to justify current ways of working. But what if taking steps to bridge the divide between doctors and patients really did result in better, less costly, more effective care? There is a growing evidence base to suggest that it will. Ten years ago, we published a theme issue on partnering with patients (www.bmj.com/content/326/7402), and other articles published before and since are now gathered in a collection on bmj.com (www.bmj.com/bmj-series/shared-decision-making). To encourage further research and thinking in this area, the BMJ plans a call for papers for a conference and theme issue on participatory care next year. More information will follow shortly. Meanwhile, we are recruiting a panel of patients and doctors to help us think about how we can reflect the shift to patient partnership. I’d welcome your thoughts.

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