After Dr Google: Peer-to-Peer Health Care

abstract

Although the majority of US adults has Internet access and gathers health information online, the Internet does not replace clinicians. People rate health professionals as their top source for technical questions such as diagnosis and treatment, but nonprofessionals (eg, friends and family) are rated higher for emotional support and quick remedies. For their most recent health issue, 21% of adults say they turned to others who have the same health condition; evidence of people’s interest in connecting with and learning from each other. People living with chronic diseases (and their caregivers) are especially likely to say they look online for peer advice. They are pioneering new ways of pursuing health by banding together and sharing knowledge, so-called peer-to-peer health care. Practical tips from fellow patients and caregivers can have far-reaching implications for clinical outcomes. As a parent of a chronically ill child observed: “We all work collaboratively, but I notice that my doctor doesn’t. After I’ve talked with my community online, I go back to him and ask, ‘What do your colleagues say about this issue?’ And it’s clear it didn’t occur to him to ask them.” Clinicians might do well to look into online patient communities and consider recommending them as resources for their patients. Clinicians might look at patient networks as a model for their own collaborative learning process as well. Linking the expertise of patients, families, and clinicians holds promise for further improving care and outcomes. Pediatrics 2013;131:S224–S225

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Dr Google is, for many Americans, a de facto second opinion. Fully 85% of adults have Internet access, and 80% of Internet users gather health information online. The Internet, however, does not replace clinicians. When asked to think about the last time they had a health issue, 71% of adults in the United States say they received information, care, or support from a health professional. Fifty-five percent say they received such help from friends and family. And 21% of adults say they turned to others who have the same health condition. It’s this last segment I find intriguing since it is evidence of people’s interest in connecting with and learning from each other. People rate health professionals as the top source for technical questions such as diagnosis and treatment; nonprofessionals are rated higher for emotional support and quick remedies. The two groups are rated equally helpful when it comes to practical advice for day-to-day health situations.

People living with chronic diseases, and the people who help care for them, are especially likely to say they look online for peer advice. If we follow the paths being blazed by these patients and caregivers, we see that they are pioneering new ways of pursuing health by banding together and sharing knowledge, something I have come to call banding together and sharing knowledge.

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Burt Minow was born in 1920 with mysterious disabilities so severe that doctors recommended institutionalization. His family not only refused, but, as he grew, forced the local school system to accommodate his hearing loss and facial paralysis. Finally diagnosed in his 70s with Moebius Syndrome, his niece, Nell Minow, used the obscure term to test new search engines in the Web’s early days. One day, she says, she got a hit:

A family with a young daughter who had Moebius had started a web page. I emailed them and told them about Uncle Burt. They wrote back instantly asking me how old he was. The very limited medical literature of the time had no record of anyone with Moebius living past their 30s. This family had located some 500 people with Moebius around the world and all of them heard for the first time that day that they could live a normal life span. And Uncle Burt heard for the first time that there were other people like him.

I retold that story at the 2012 conference of the Moebius Syndrome Foundation, in front of an audience filled with people who, if they had been born 100 years ago, would have faced either the loss of their child or life in an institution. Instead, they use the Internet to connect with each other and thrive. One father told me that when his daughter was born unable to suck, doctors offered the only solution they knew: a feeding tube. The family scoured the Internet for alternatives, found a site devoted to cleft palate, and worked with doctors on a creative feeding solution for their infant. The Internet filled in where traditional medicine fell short. A mother at the conference told a different story. When her infant daughter had been fitted with a feeding tube, it meant she couldn’t wear onesies, just T-shirts, to provide easy access. But infants wriggle and their shirts ride up in the back, an uncomfortable, wrinkled mess. After a few months of frustration with her infant’s T-shirt problem, this mom realized that she could just cut a hole in a onesie: voila! A more comfortable shirt. It seems like an obvious trick, but none of her infant’s doctors or nurses thought to tell her about it, and she wasn’t yet connected to an online community of patients and caregivers. And by the way, she continued, why didn’t anyone at the hospital tell her there was a pump for overnight feedings? For the first 6 months of her infant’s life, this mom got up every 4 hours to administer formula when, if she’d had the pump, she could have been sleeping. It didn’t occur to the clinicians to tell her, but it probably would have occurred to another parent of an infant with a feeding tube.

These practical tips are exactly what fellow patients and caregivers know best, and they can have far-reaching implications for clinical outcomes. A third parent at the conference observed: “We all work collaboratively, but I notice that my doctor doesn’t. After I’ve talked with my community online, I go back to him and ask, ‘What do your colleagues say about this issue?’ And it’s clear it didn’t occur to him to ask them. How can we encourage doctors to do what we do: work together?”

As we move past the Dr Google stage of the Internet’s impact on health and health care, clinicians might do well to look into online patient communities and consider recommending them as resources for their patients. Clinicians might look at patient networks as a model for their own collaborative learning process as well.

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