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Book Reviews

A Review of *Rebel Health: A Field Guide to the Patient-Led Revolution in Medical Care*

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Rebel Health: A Field Guide to the Patient-Led Revolution in Medical Care. Susannah Fox. Cambridge, MA: MIT Press, 2024. 200 pages, $29.95 hardcover.
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Susannah Fox's *Rebel Health: A Field Guide to the Patient-Led Revolution in Medical Care* offers a timely examination of the transformative power of patient-led movements in healthcare. Drawing on two decades of interviews from patients, survivors, and caregivers, Fox illustrates how individuals and their communities are challenging traditional medical hierarchies and driving innovation in diagnostics, treatment, and healthcare policy. By highlighting the diverse roles that individuals and organizations alike play in facilitating more responsive, equitable, and patient-oriented healthcare, Fox's *Rebel Health*—equal parts testimonial, call to action, and practical "field guide"—equips readers to recognize issues of inequity and inefficiency in our healthcare system, communicate them to others, and take action against them.

Patient-Led Medical Change: Past and Present

Fox's framework of "rebel health" draws from a legacy of other "rebels on the front lines of an underground movement to improve health and health care" (p. ix). Her timeline begins with the founding of the United Order of Tents in 1867, which was created by two formerly enslaved women to provide medical and financial assistance to other Black women (p. 3). Other notable movements included the founding of Alcoholics and Narcotics Anonymous in 1935 and 1953, respectively, to aid and support people in addiction recovery, the Black Panther Party's 1971 initiative for sickle cell anemia testing, and the founding of HIV/AIDS advocacy movements like the Denver Principles (1983) and the AIDS Coalition to Unleash Power (1992) to improve the outcomes and experiences for HIV+ patients and their families (p. 4). In each of these cases, Fox highlights how marginalized patients and their local communities came together to forge connections, share knowledge, advocate for policy changes, and ultimately save lives when the mainstream medical system dismissed, overlooked, or failed to meet their needs.

Fox notes that these movements all share another thing in common: They existed before the user-generated internet became part of our daily lives. This has created new opportunities for problem-solving, coalition-building, and amplifying patient voices, enabling contemporary movements for health equity to grow more rapidly and reach broader audiences than ever before. The internet has also enabled patients to forge timely connections with other people who have experienced the same challenges or symptoms, exemplifying what Fox refers to as the capacity to find a "just-in-time someone-like-you" (p. 7) without geographic constraints.

However, the rise of the user-generated internet also brings significant challenges, particularly the proliferation of misinformation. While the accessibility of online platforms empowers patient-led movements to gather information, share experiences, and build coalitions with allies, Fox emphasizes that the spread of inaccurate or harmful medical advice poses a threat to *everyone*, not just medical providers who are sometimes assumed to want unilateral control of the medical information that circulates online. Adopting a "prosocial, not anti-science" perspective (p. 12) is one way Fox's participants navigate this challenge, actively collaborating with medical providers, innovators, and researchers to ensure the information they share is accurate, evidence-based, and safe for wider dissemination. This lens, which is woven throughout the stories and tips in the book, emphasizes one of *Rebel Health*'s clearest takeaways: by fostering an ethos of shared accountability and emphasizing the value of reliable knowledge, patient-led movements can harness the power of digital tools without compromising the integrity of their advocacy efforts.

Patient Archetypes

The book is organized around four archetypes: seekers, networkers, solvers, and champions. Each section is grounded in the real stories of Fox's research participants and collaborators—patients, caregivers, providers, and innovators—who identified gaps in the mainstream medical system and took action to address them, often leveraging digital tools and the power of "peer-to-peer health care" online (p. 9). This enables patients to overcome what Fox identifies as the two primary barriers to effective and efficient healthcare interventions: someone's needs being invisible to the mainstream medical system and someone's needs not being met by the medical system. Woven throughout these chapters are accounts of how the four archetypes leverage their skills to move patient experiences and conditions towards the upper right-hand quadrant of being visible to the mainstream healthcare system and having their needs met.

Seekers

Seekers are defined by their drive to source information. They "go out on the hunt" (p. 10), asking questions, searching for resources, and looking for answers. Fox notes that people often become Seekers when mainstream medical interventions fail to recognize their problems or address their needs, leading to frustration and a sense of abandonment by the healthcare system. For many, the first step is storytelling—sharing their health journeys to process their experiences and reclaiming agency over their care. By articulating their struggles and searching for answers, Seekers like Delina Pryce McPhaull (Chapter 3) reveal how piecing together fragmented resources and experiences is often the first step toward solving a problem. For instance, McPhaull tirelessly searched online for something that would help her brother-in-law with Parkinson's disease take his daily pills despite the tremors that made handling such small items difficult.

Networkers

Networkers approach health and medical problem solving through a social lens. They "pool resources" (p. 10) by connecting directly with other people, who are valuable sources of knowledge and community. Unlike Seekers, who focus more on individual exploration, Networkers prioritize building and leveraging connections to access diverse perspectives and solutions. They are often the ones who organize support groups, facilitate information exchange, and amplify shared experiences. Through this process, Networkers transform personal frustration into collective knowledge and help to create and maintain resilient, informed communities that challenge traditional hierarchies in healthcare and advocate for more inclusive, patient-centered approaches. For example, Fiona Lowenstein (Chapter 4), the founder of queer feminist health collective Body Politic, created a subgroup of this organization to facilitate conversations amongst other early long COVID-19 patients. With the other members of this group, Lowenstein successfully “fill[ed] in knowledge gaps and act[ed] as a backstop against misinformation and miscalculation” (p. 52) about an emerging and poorly understood condition.

Solvers

Solvers take their individual experiences and the collective wisdom of their communities to “attack problems” with a proactive, innovative mindset (p. 11). They move beyond seeking information and building networks to actively “test and develop new concepts, codes, and interventions” (p. 11). Whether designing open-source medical devices, developing new care protocols, or coding tools to track and analyze symptoms, Solvers are hands-on in their approach. As Fox describes, the diabetes patient community exemplifies this Solver mentality: patients like Ben West, Dana Lewis, and Scott Leiband worked together to make glucose monitor alarms louder, while Lane Desborough, Ross Naylor, Kevin Lee, and John Costick hacked their devices so their children’s life-saving alerts could be shared with a caregiver’s smartwatch or phone (Chapter 7). With their do-it-yourself attitude to healthcare management, Solvers serve as a bridge between identifying problems and solving them, showcasing the potential for patient-led ingenuity and innovation.

Champions

Champions amplify the work of other archetypes by “tak[ing] new ideas and innovations to scale,” transforming local efforts into broader systemic change (p. 11). They connect patient-led initiatives with the wider healthcare ecosystem, leveraging their skills, platforms, or influence to advocate for widespread adoption of solutions. Champions are often skilled communicators and strategists, capable of framing the work of Seekers, Networkers, and Solvers in ways that resonate with diverse audiences, including policymakers, healthcare providers, and the public. For example, Fran Visco, a breast cancer patient and member of the National Breast Cancer Coalition (NBCC), drew from organizing grassroots movements like ACT UP to partner with local policymakers and the National Cancer Institute to ensure patients got a say in breast cancer research priorities (Chapter 10). In the early 1990s, patients' inclusion in such matters was almost unheard of, and Visco's efforts to find allies in legal and governmental spaces position her as a Champion: Someone who helps patient-led innovations gain the visibility and legitimacy needed to disrupt entrenched systems and create lasting impact.

Concluding Thoughts

From the makerspace to the hospital room and the Reddit forum to Capitol Hill, Fox's field guide offers a useful starting point for anyone looking for actionable strategies to act against medical injustice and inequities. Technical and professional communication (TPC) and rhetoric of health and medicine (RHM) readers, particularly those who align their work in participatory research methods or other collaborative frameworks, may appreciate the model for centering non-academic voices in academic research. Furthermore, because each archetype chapter also details struggles that each group may face and tips for overcoming these barriers, readers will likely find something useful, whether they are seeking to gather information, amplify patient voices, foster collaborative networks, or implement practical solutions to address systemic gaps in healthcare. Finally, instructors may find the scenarios in Chapter 11 particularly useful as a pedagogical tool, with each one providing an overview of a problem illustrated within the Rebel Health Matrix and offering suggestions for how each archetype might contribute to "solving" it.

And yet, while Fox mentions how the problems facing healthcare are multifaceted and deeply entangled with systems of oppression like racism, classism, sexism, and ableism, the stories included in *Rebel Health* would benefit from a more thorough exploration of how Seekers, Networkers, Solvers, and Champions work towards clinical reform with specific attention to these discriminatory structures. This deeper focus would enrich the Rebel Health Matrix by critically examining how power, positionality, and privilege (Walton, Moore, & Jones, 2019) create distinct barriers—and demand equally distinct solutions—for marginalized patient populations striving for equity and inclusion in healthcare. By integrating a more robust intersectional analysis, Fox's field guide could more effectively highlight the nuanced strategies required to address systemic inequities, further positioning itself as an indispensable toolkit and roadmap for all those working to transform our medical care system from the ground up.

References

Walton, Rebecca., Moore, Kristen, & Jones, Natasha (2019). *Technical Communication After the Social Justice Turn: Building Coalitions for Action*. Routledge.

Author Bio

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