

Putting Patient Concerns on the Policy Agenda: The Need for a Unified, Independent Patient Lobby

Gyan Moorthy*

ABSTRACT

The interests of patients at most levels of policymaking are represented by a disconnected patchwork of groups focusing on disease, age, ethnicity, or gender, like Susan G. Komen, the AARP, and the NAACP. These groups compete with one another for funding and are ill-equipped to compete with groups representing the interests of healthcare professionals, pharmaceutical and medical device companies, hospitals, and insurance providers. The result is an imbalance – big health has more financing and power, resulting in healthcare policy that does not adequately reflect patient concerns, especially the concerns of poor or otherwise vulnerable patients. These big health groups also misrepresent patient concerns to further their own interests, and patients are seldom in a position to push back. While some suggest the creation of a unified, independent patient lobby to interface directly with policymakers and the public, it is not altogether clear how such a lobby could be formed or how to focus its efforts to have the intended impact. Though there are structural obstacles to the development of a unified, independent patient lobby, such a lobby could successfully pressure the appropriate officials or lawmakers to address the issues that affect most patients. Today's culture values patient input, and with key ACA provisions at risk, patients should begin organizing so they can influence policymaking – potentially with a little help from bureaucrats. To get off the ground, a patient lobbying group analogous to PhRMA, the AHA, or the AMA would have to commit to a big tent philosophy, and it would have to fight hard to maintain its independence.

Keywords: Patient, age, disease, gender, AMA, philosophy, policymaking, big health

INTRODUCTION

Currently, the interests of patients at most levels of policymaking are represented by a disconnected patchwork of groups focusing on disease, age, ethnicity, or gender, like Susan G. Komen, the AARP, and the NAACP. These groups compete with one another for funding and are ill-equipped to compete with groups

* Gyan Moorthy, MS Candidate Columbia University

representing the interests of healthcare professionals, pharmaceutical and medical device companies, hospitals, and insurance providers. The result is an imbalance – big health has more financing and power, resulting in healthcare policy that does not adequately reflect patient concerns, especially the concerns of poor or otherwise vulnerable patients. These big health groups also misrepresent patient concerns to further their own interests, and patients are seldom in a position to push back. While some suggest the creation of a unified, independent patient lobby to interface directly with policymakers and the public, it is not altogether clear how such a lobby could be formed or how to focus its efforts to have the intended impact.

ANALYSIS

Nearly all Americans will be patients at some point in their life, so patients are a diverse group. They have a range of unique interests informed by their disease, age, location, socioeconomic situation and, to some extent, political views. The differences that exist between individual patients are much greater than the differences between different pharmaceutical companies or even different physicians. But this does not mean that patients have nothing in common. Most patients have similar expectations about the confidentiality of their records or protections that should be afforded to them if their treating physician asks them to participate in a research trial. They want to be able to receive care at the nearest emergency department and to choose their doctors. They all hate surprise medical billing, and most are troubled by the high price of prescription drugs.

A strong patient lobby might be able to successfully pressure Congress into taking action on these issues, or at least help advance the conversation by serving as a counterweight to the influence of other lobbies. The 2001 Bipartisan Patient Bill of Rights, sponsored by Senators John McCain (R, AZ) and Edward Kennedy (D, MA), would have expanded HMO coverage requirements and enabled employees to sue their employers if their claims were denied.¹ It failed after a sustained lobbying and public information campaign by insurance companies and employers, linked through the deceptively-named Health Benefits Coalition.² Several efforts to end surprise medical billing and promote price transparency have similarly failed or been stalled, in part because the American Hospital Association (AHA) complained that the changes would be too difficult to implement during the COVID-19 pandemic.³ The Affordable Care Act (ACA) enacted some popular changes, including an elimination of coverage exclusions for people with pre-existing conditions, closure of the Medicare Part D “donut hole,” and expansion of coverage to age 26.⁴ A patient lobby might have been able to secure more benefits, e.g., coverage requirements for dental, vision, and mental health services.

But the need to protect the ACA may be a better impetus for the formation of a strong patient lobby. The ACA has already been gutted by the Trump Administration’s actions to end certain insurance subsidies and Congress’s decision to repeal the penalty associated with the individual mandate, resulting in premium increases.⁵ Cuts to funds that facilitate sign-ups on the exchanges also resulted in premium increases. The individual mandate is the subject of yet another Supreme Court challenge. If the legislation is struck down, already weakened protections for pre-existing conditions will be in jeopardy.⁶ The changes to the ACA may galvanize patients to organize. Already, the general public’s interest in health policy has increased and appears to remain strong, unlike the waning enthusiasm following the failure of the Clinton healthcare plan.

Nevertheless, there are significant practical and cultural obstacles to the formation of a unified, independent patient lobby in the United States, and limits to what such a lobby could reasonably accomplish. Patients are a diverse group, and on a variety of issues, they can hardly be considered a group at all. The healthcare system consists of many interlocking parts. A provision to significantly benefit one

group of patients, e.g., those on Medicaid, may not only come at the expense of insurance companies, but at the expense of other groups of patients. It is doubtful that most better-off patients would be willing to make sacrifices for the more disadvantaged among them. Research funding is limited, and if it is allocated to curing childhood leukemia, it may not be allocated to curing joint disease in the elderly. Then there is the problem of what is actually necessary to promote patient welfare. Patients often do not know exactly what will benefit them, whether their town really *needs* a Level IV neonatal intensive care unit or whether pharmaceutical companies should be able to advertise off-label drug uses. Even if they agree on general problems, they may not agree on solutions.

Patient groups are also susceptible to industry influence. The prestige of larger, well-established patient advocacy groups makes them attractive investments. According to a 2017 study in the *New England Journal of Medicine*, more than 80 percent of the largest 104 patient advocacy groups accepted money from drug, medical device, and biotechnology companies. Several groups did not disclose sources of funding or did not disclose what proportion of their budget came from each donor. Many also have company executives on their governing boards.⁷ When diverse patient advocacy groups have banded together to increase their clout, industry has always been a part of the conversation. The results have been predictable.

For example, the American Cancer Society, the American Heart Association, and the American Diabetes Association, as well as various pharmaceutical and biotechnology companies are all members of the National Health Council, an organization founded to advocate for those living with chronic diseases and disabilities. These companies provide the majority of the Council's funding and have strong representation on its board. In 2016, the Council came out strongly in favor of a deal between the FDA and pharmaceutical companies to speed the approval of new drugs as part of the reauthorization of the Prescription Drug User Fee Act. It also campaigned energetically for the 21st Century Cures Act, which was criticized by watchdogs as another attempt at weakening the FDA's protection of consumers from dangerous drugs and medical devices.⁸ It is possible that patients really believed they would benefit from these changes, and perhaps some will, but the changes will chiefly benefit the pharmaceutical industry, the legitimacy of which is boosted by its partnerships with patient groups.

Since the 1960s, medical culture has undergone dramatic changes. Patients are seen more as partners in health and well-being than passive slabs of clay. Their individual value systems and social context are incorporated into care plans. The result has been more satisfied patients, more cost-effective care delivery, and better health outcomes.⁹ These productive partnerships could extend into policymaking by expanding the physician-patient dyad, or physician-patient-hospital triad, to include more actors. Keeping interest high and ensuring that the voices of some patients do not drown out the voices of others will be a challenge.

To begin to broaden patient groups at the local level, hospitals and clinics can host community meetings, where patients, healthcare providers, and administrators talk about the issues affecting them and brainstorm solutions. Trust grows over time. Perhaps patients can secure more forgiving medical debt repayment programs, reforms to arbitration procedures, more permissive visitation policies, or transparency in ethics and quality improvement committee deliberations and recommendations. Local patient groups can help steer conversations and exert gentle pressure, where necessary. They can ensure that hospitals and physicians do not blindly follow national guidelines but tailor them to meet the specific needs of the local population. They can publish lists of institutions or physicians who engage productively with them, potentially costing others goodwill and business.

State and national institutions involved in health policy creation can also attempt to incorporate patient voices into their deliberations. Unlike in Germany, where all Health Committee hearings feature testimony

from the same several *Spitzenverbände* (national associations of various interests) and all meetings and briefs are made accessible online, US legislation is deliberated in a haphazard, back-and-forth process that involves a lot of back-room dealing.¹⁰ That is, there is no single table at which American patient groups can sit to have far-reaching impact; they must establish themselves at multiple levels and learn to play a lobbying game that other interests have been playing a lot longer. But state public health departments in addition to the Centers for Medicare & Medicaid Services (CMS) and the Department of Health and Human Services (HHS) could establish public/patient advisory boards or include patient advocates as agenda setters in various sub-departments. Some short-term results could be more generous Medicaid eligibility and coverage requirements or accelerated Certificate-of-Need hearings for the creation of new medical infrastructure.

In the long-term, the institutionalized representation of patient voices at various places in the bureaucracy could provide the basis for the development of a unified patient lobby. These boards could vie for increased influence through membership in a formalized, state, regional, or national organization. Local patient advocacy groups could be incorporated as well.¹¹ After consolidation, the lobby might expand its purview and meaningfully pressure legislatures on issues like surprise medical billing, high prescription drug prices, and privacy protections. The lobby's success may depend on its commitment to issues on which there is little disagreement between patients. To ensure the continued independence of the patient lobby, sunshine laws mandating funding transparency could be expanded.¹²

Importantly, this unified patient lobby could include existing patient advocacy groups that could continue to pursue their own goals independently, much as various pharmaceutical companies, hospitals, and physicians do outside of the Pharmaceutical Research and Manufacturers of America (PhRMA), the AHA, or the American Medical Association (AMA). The whole is greater than the sum of its parts: a unified patient lobby can (1) push for action on issues where patients generally agree, like surprise medical billing, (2) indirectly further the goals of each constituent organization, e.g., through a push for global increases in disease and disability research, and (3) slowly raise the level of public debate, encouraging and sustaining broader and more informed public attention to the health policy development process.

Ideally, a unified patient lobby would also elevate previously-unheard voices. As patients with various backgrounds and interests work with one another to achieve their common goals, they may find that they have other things in common as well. They may also see that improving the health of some parts of the population has important spillover effects for others. For example, healthy workers are more productive, and healthy parents can be more engaged in their children's lives, setting them up for success. In the same way that the AARP has special divisions to promote the particular interests of its black and Hispanic members, an umbrella patient lobbying group could allocate some resources to promoting the interests of disadvantaged patients. Most importantly, however, it could create a tighter sense of community among patients, pushing society to become more compassionate and understanding.

James Morone would warn that creating mechanisms for increasing the representation of disaffected or marginalized groups is not a panacea. This "democratic wish" could begin a social and political process that ends in circumstances similar to those that initially brought it about: political stalemate.¹³ But I argue that the stalemate is avoidable, and that group representation can further democracy. Disease, age, ethnicity, and gender groups like the American Association of Pediatrics (AAP), which campaigns for policies that benefit children's health, should continue to represent patient interests as well. Within the unified patient lobby, experts on cost and quality, including those who suggest unpopular solutions like certain changes to

Medicare, should be heard and, in many cases, heeded. A unified, independent patient lobby could help to restore balance to a policymaking process dominated by other well-funded, well-organized interests.

CONCLUSION

Patients in the United States are a diverse group, with complicated and often contradictory interests. However, they do share some common interests including expectations of confidentiality, freedom to choose their providers, and a hatred of surprise medical billing. Though there are structural obstacles to the development of a unified, independent patient lobby, such a lobby could successfully pressure the appropriate officials or lawmakers to address the issues that affect most patients. Today's culture values patient input, and with key ACA provisions at risk, patients should begin organizing so they can influence policymaking – potentially with a little help from bureaucrats. To get off the ground, a patient lobbying group analogous to PhRMA, the AHA, or the AMA would have to commit to a big tent philosophy, and it would have to fight hard to maintain its independence. With time, it might become more ambitious and catalyze substantive changes in the arena of patient access and care.

¹ US Congress. Senate. 2001. Bipartisan Patient Protection Act. S1052. 107th Congress. Introduced in Senate June 14, 2001. <https://www.congress.gov/107/bills/s1052/BILLS-107s1052es.pdf>.

² Brubaker, Bill. 2001. "Patients' Bill's Foes Back Away From Ad." *Washington Post*, April 12, 2001. <https://www.washingtonpost.com/archive/business/2001/04/12/patients-bills-foes-back-away-from-ad/53377e06-e173-4bd0-8e5b-797c172c34fc/>.

³ LaPointe, Jacqueline. 2020. "Surprise Billing Action Needed, But Hospitals Urge Congress to Wait." *RevCycleIntelligence*, August 6, 2020. <https://revcycleintelligence.com/news/surprise-billing-action-needed-but-hospitals-urge-congress-to-wait>.

⁴ Engel, Jonathan. 2018. *Unaffordable*. Madison and London: The University of Wisconsin Press.

⁵ Kamal, Rabah, Rachel Fehr, Marco Ramirez, and Katherine Horstman. 2018. "How Repeal of the Individual Mandate and Expansion of Loosely Regulated Plans Are Affecting 2019 Premiums." KFF. October 26, 2018. <https://www.kff.org/health-costs/issue-brief/how-repeal-of-the-individual-mandate-and-expansion-of-loosely-regulated-plans-are-affecting-2019-premiums/>.

⁶ Simmons-Duffin, Selena. 2019. "Trump Is Trying Hard To Thwart Obamacare. How's That Going?" *NPR*, October 14, 2019. <https://www.npr.org/sections/health-shots/2019/10/14/768731628/trump-is-trying-hard-to-thwart-obamacare-hows-that-going>.

⁷ McCoy, Matthew S., Michael Carniol, Katherine Chockley, John W. Urwin, Ezekiel J. Emanuel, and Harald Schmidt. 2017. "Conflicts of Interest for Patient-Advocacy Organizations." *New England Journal of Medicine* 376 (9): 880–85. <https://doi.org/10.1056/NEJMSr1610625>.

⁸ Hilzenrath, David S. 2016. "In FDA Meetings, 'Voice' of the Patient Often Funded by Drug Companies." Project On Government Oversight (POGO). <https://www.pogo.org/investigation/2016/12/in-fda-meetings-voice-of-patient-often-funded-by-drug-companies/>.

⁹ Vahdat, Shaghayegh, Leila Hamzehgardeshi, Somayeh Hessam, and Zeinab Hamzehgardeshi. 2014. "Patient Involvement in Health Care Decision Making: A Review." *Iranian Red Crescent Medical Journal* 16 (1). <https://doi.org/10.5812/ircmj.12454>.

¹⁰ Redman, Eric. 2000. *The Dance of Legislation: An Insider's Account of the Workings of the United States Senate*. 1st edition. Seattle: University of Washington Press.

¹¹ This is just one possible means by which a unified patient lobby could be formed. Others include slowly, in a grass-roots fashion, by wealthy benefactors or through consolidation of existing disease-specific groups in a more substantive way than has

been done to date. I do not claim to know which is most feasible, or if any of them are. But even if they are not, it is important to think about, as future leaders, interested parties, etc. can shape culture and institutions such that they become feasible.

¹² Karas, Laura, Robin Feldman, Ge Bai, So Yeon Kang, and Gerard F Anderson. 2019. "Pharmaceutical Industry Funding to Patient-Advocacy Organizations: A Cross-National Comparison of Disclosure Codes and Regulation" 42 (2): 33.

¹³ Morone, James. 1998. *The Democratic Wish: Popular Participation and the Limits of American Government*. New Haven and London: Yale University Press.