

VIEWPOINT

The New Age of Patient Autonomy

Implications for the Patient-Physician Relationship

Madison K. Kilbride, PhD

Department of Medical Ethics and Health Policy, Perelman School of Medicine, University of Pennsylvania, Philadelphia.

Steven Joffe, MD, MPH

Department of Medical Ethics and Health Policy, Perelman School of Medicine, University of Pennsylvania, Philadelphia; and Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania.

The rejection of medical paternalism in favor of respect for patient autonomy transformed the patient-physician relationship. Historically, medicine and society subscribed to the ethical norm that the physician's main duty was to promote the patient's welfare, even at the expense of the latter's autonomy. A central assumption of the paternalistic framework was that physicians, because of their medical expertise, knew best what was in the best interest of patients. Accordingly, physicians decided which interventions would promote patients' welfare; patients, for their part, were expected to comply.

The decades since the 1950s have seen an increasing emphasis on patients' rights to accept or decline recommended treatment. The rejection of medical paternalism did not, however, overturn physicians' control in their relationships with patients. In theory, physicians could no longer make unilateral decisions about their patients' care, but in practice, they retained gatekeeping authority by virtue of their monopoly over medical information and most medical resources. This characterization of the patient-physician relationship, with patients in control of their medical decisions but

and the patient expresses his or her values and preferences. In some cases, the physician may need to help the patient identify or clarify his or her values and goals of care in light of the available treatment options.²

Although there is general consensus that patients should participate in and ultimately make their own medical decisions whenever possible, most versions of shared decision making take for granted that the physician has access to knowledge, understanding, and medical resources that the patient lacks. As such, the shift from medical paternalism to patient autonomy did not wholly transform the physician's role in the therapeutic relationship.

In recent years, however, widespread access to the internet and social media has reduced physicians' dominion over medical information and, increasingly, over patients' access to medical products and services. It is no longer the case that patients simply visit their physicians, describe their symptoms, and wait for the differential diagnosis. Today, some patients arrive at the physician's office having thoroughly researched their symptoms and identified possible diagnoses. Indeed, some patients who have lived with rare diseases may even know more about their conditions than some of the physicians with whom they consult.

The expanding availability of direct-to-consumer (DTC) tests and screens has further diminished physicians' control over patients' access to medical resources. Some tests that

once required expensive equipment and an office or hospital visit can now be done by a consumer at home. For example, consumers can perform a do-it-yourself electrocardiogram on a \$99 device that interfaces with a smartphone app. The use of DTC laboratory tests is also increasing. These tests run the gamut of scientific legitimacy. Some, such as an at-home blood test for food sensitivity, do not meet standards of clinical validity.³ Others, by contrast, are considered high quality and, until recently, would have required a physician's order. For example, depending on the state, consumers can order an array of laboratory tests, including complete blood cell counts, comprehensive metabolic panels, hepatitis C screening, and a variety of sexually transmitted disease screening panels.

There is also a burgeoning market for health-related DTC genetic tests. Notably, in April 2017, the Food and Drug Administration (FDA) approved 23andMe to market a genetic test that assesses consumers' risk of developing 10 different conditions, including late-onset Alzheimer disease, Parkinson disease, and hereditary thrombophilia. Recently, the FDA

Today's patients, informed by the internet and social media, are increasingly less dependent on their physicians for access to medical information and resources.

dependent on their physicians for access to information and most medical products and services, is no longer accurate. Medicine has entered a new age of patient autonomy. Today's patients, informed by the internet and social media, are increasingly less dependent on their physicians for access to medical information and resources. This revolutionary change requires a fundamentally different understanding of the patient-physician relationship.

The New Age of Patient Autonomy

The abandonment of strong medical paternalism led scholars to explore alternative models of the patient-physician relationship that emphasize patient choice.¹ Shared decision making gained traction in the 1980s and remains the preferred model for health care interactions. Broadly, shared decision making involves the physician and patient working together to make medical decisions that accord with the patient's values and preferences. Ideally, for many decisions, the physician and patient engage in an informational volley—the physician provides information about the range of options,

Corresponding

Author: Steven Joffe, MD, MPH, Department of Medical Ethics and Health Policy, Perelman School of Medicine, University of Pennsylvania, 423 Guardian Dr, Blockley Hall 1413, Philadelphia, PA 19104-4884 (joffes@upenn.edu).

authorized 23andMe to test for 3 specific *BRCA1* and *BRCA2* mutations that are known to substantially increase a woman's risk of developing breast and ovarian cancer.⁴

The Physician's Role in the Age of Increased Patient Autonomy

Expanded access to information and to a variety of health-related products and services will bring new opportunities for patients to direct their own health care. It will also bring new challenges for physicians who must manage the downstream consequences of tests and screens they did not order. Most important, the new age of patient autonomy will necessitate that physicians reconceptualize their role in the patient-physician relationship. In this new age of autonomy, physicians may need to act in the following 3 capacities.

First, physicians will serve as consultants or advisors to patients who will increasingly direct their own care. Unencumbered access to information and DTC tests and screens, while potentially autonomy enhancing, can also lead to confusion and uncertainty. When patients have questions or concerns about information obtained online or about the significance of a DTC test result, they may contact their physicians to interpret an ambiguous finding, recommend medical management options, and if necessary, refer them to the appropriate specialist.

Second, physicians will continue to perform diagnostic and therapeutic procedures that patients are not able to carry out. Moreover, physicians will still need to make judgments about whether a given procedure is appropriate for a patient. Even in the new age

of autonomy, there is still a need for physicians to exercise professional agency.⁵

Third, although physicians will still be the gatekeepers of many medical resources, the function of gatekeeping will change. The availability of DTC products and services has pushed physicians' gatekeeping back a level. No longer in control of patients' initial access to an expanding array of tests, physicians will increasingly act as gatekeepers to follow-up services. For example, how should a well-informed primary care physician respond when a healthy middle-aged patient requests a referral to a hematologist after learning (eg, through a DTC genetic test) that he is heterozygous for the factor V Leiden mutation associated with an increased risk of thrombophilia? One of the many challenges for physicians in the new age of autonomy is how to advocate for care that is driven by medical need rather than solely by patient demand.

Conclusions

Unmediated access to medical information and to an increasing array of health-related products and services has radically altered the balance of power between physician and patient. But while patients can research their symptoms and order many laboratory and genetic tests online, they will continue to depend on their physicians for advice, procedural expertise, and access to restricted medical services. By appreciating how the internet, social media, and other factors are transforming medical relationships, physicians will be better able to meet their patients' health care needs in the age of enhanced patient autonomy.

ARTICLE INFORMATION

Published Online: October 15, 2018.
doi:[10.1001/jama.2018.14382](https://doi.org/10.1001/jama.2018.14382)

Funding/Support: Dr Joffe reports receipt of a grant to support Dr Kilbride: a T32 training grant from the National Human Genome Research Institute (HG009496).

Role of the Funder/Sponsor: The National Human Genome Research Institute had no role in the preparation, review, or approval of the manuscript or decision to submit the manuscript for publication.

Additional Contributions: The authors are grateful to Holly Fernandez Lynch, JD, MBE (University of

Pennsylvania Perelman School of Medicine), and Franklin G. Miller, PhD (Cornell University School of Medicine) for comments on an earlier draft of this article. Neither received compensation for their work.

REFERENCES

1. Brock DW. The ideal of shared decision making between physicians and patients. *Kennedy Inst Ethics J*. 1991;1(1):28-47. doi:[10.1353/ken.0.0084](https://doi.org/10.1353/ken.0.0084)
2. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA*. 1992;267(16):2221-2226. doi:[10.1001/jama.1992.03480160079038](https://doi.org/10.1001/jama.1992.03480160079038)
3. Carr S, Chan E, Lavine E, Moote W. CSACI position statement on the testing of food-specific IgG. *Allergy Asthma Clin Immunol*. 2012;8(1):12. doi:[10.1186/1710-1492-8-12](https://doi.org/10.1186/1710-1492-8-12)
4. Gill J, Obley AJ, Prasad V. Direct-to-consumer genetic testing: the implications of the US FDA's first marketing authorization for BRCA mutation testing. *JAMA*. 2018;319(23):2377-2378. doi:[10.1001/jama.2018.5330](https://doi.org/10.1001/jama.2018.5330)
5. Brett AS, McCullough LB. Addressing requests by patients for nonbeneficial interventions. *JAMA*. 2012;307(2):149-150. doi:[10.1001/jama.2011.1999](https://doi.org/10.1001/jama.2011.1999)