

HHS Public Access

Author manuscript

Health Aff (Millwood). Author manuscript; available in PMC 2016 April 28.

Published in final edited form as:

Health Aff (Millwood). 2013 February; 32(2): 401-407. doi:10.1377/hlthaff.2012.1081.

Providers, Payers, The Community, And Patients Are All Obliged To Get Patient Activation And Engagement Ethically Right

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Abstract

Active and engaged patients seek the understanding, knowledge, and skills to promote their own health. Efforts to promote such patient activation and engagement are ethically justified because they are consonant with the well-established principle of respect for persons and, as the evidence shows, because they are likely to produce better outcomes for patients. Yet patient activation and engagement can also go ethically awry if, for example, nonadherent patients are abandoned or are unduly disadvantaged by punitive policies and practices, or if the conditions for successful activation and engagement are missing. In this article we discuss the ethical issues and responsibilities that pertain to patients, clinicians, health care organizations, delivery systems, insurers, payers, and communities. For example, physicians or payers could hold patients blameworthy for not following recommendations, but we suggest that a better approach would be for providers and payers to empower patients to effectively share responsibility for defining goals and achieving them. An ethical approach to patient activation and engagement should place obligations not only on patients but also on clinicians, health care organizations and delivery systems, insurers, and communities.

Any efforts at patient activation and engagement, such as sharing treatment decisions between patients and physicians, assume that patients should not be treated as passive recipients of care but as active participants in the promotion of their own health. In this article, we offer an ethical justification for activation and engagement. We also describe the responsibilities that must be met by patients, clinicians, health care organizations and delivery systems, insurers and other payers, and communities, if the full potential of activation and engagement is to be realized and ethical pitfalls avoided.

We use the definition of *patient activation* proposed and used by Judith Hibbard and colleagues. Under this definition, activated patients believe they have important roles to play in managing their own care, collaborating with providers, and maintaining their health; they know how to manage their condition and maintain functioning for as long as possible; and they have the skills and behavioral repertoire to manage their condition, collaborate with their health providers, and obtain appropriate and high-quality care. ¹

We also use the definition of *patient engagement* offered by Donna Cryer, a patient advocate and the president of the American Liver Foundation: "Properly done, patient engagement in action looks like shared responsibility between patients (and their families if applicable), health care practitioners (the entire team: surgeons, physicians, nurses), and healthcare administrators (providers of the infrastructure and payment models) to co-develop pathways to optimal individual, community and population health. Patient engagement brought to life means involving patients and caregivers in every step of the process, providing training or financial support if necessary."²

We endorse such a broad definition because factors beyond the health care arena have a powerful influence on health, including how a person develops during the first few years of life, how much education a person obtains, whether a person is able to find work and whether the workplace poses any health risks, whether a person lives in a safe neighborhood and has adequate housing and access to sufficient nutritious food, how much a person earns, and whether a person has adequate social support or faces discrimination.^{3,4}

Ethical Justification For Patient Activation And Engagement

Patient activation and engagement are justifiable on two ethical grounds.

The first is that we should pursue these strategies because they are consonant with the principle of respect for persons. This justification is a deontological one, which is a type of moral justification that focuses on the rights that are owed to people and the duties that others are required to carry out to fulfill those rights.⁵

In the literature of moral and political philosophy, the idea of respect for persons is usually understood as a kind of respect that all people are owed just because they are persons, regardless of social position, personal characteristics or achievements, or moral merit. Patient activation and engagement are consistent with respect for people, in that these strategies aim to enhance the patient's right to self-determination. They do so in particular by allowing patients to set health goals for themselves and by promoting their ability to be self-actualizing—that is, to help them accomplish these goals themselves.

The second justification is that we should pursue these strategies because, when employed, they are likely to lead to better health outcomes. This justification is a consequentialist one, which is based on the good that can come of our actions. The consequentialist argument for endorsement of patient activation and engagement is based on evidence that activated patients are healthier than those who are not similarly activated, that it is possible to assist patients in becoming more activated and engaged, and that positive health outcomes follow. For instance, adults with chronic conditions and high Patient Activation Measure scores have been shown to be significantly more likely to perform self-management behaviors, use self-management services, and report high medication adherence, compared to patients with the lowest Patient Activation Measure scores.

Activated patients have been reported to be ten times more likely to have high patientsatisfaction scores and five times more likely to report high quality-of-life scores. They have also reported significantly higher physical and mental functional status scores, compared to

those with the lowest scores.⁷ Patients who have been helped to read their medical record and coached to ask questions and negotiate medical decisions with their physicians have more involved interactions with their physicians and fewer limitations imposed by disease on their functional ability than patients in a control group.⁸

Patients with heart disease, lung disease, stroke, or arthritis who participated in a chronic disease self-management program have been shown to improve in several ways, including the length of time they can exercise and how healthy they consider themselves. Those in the program were also less likely to be distressed about their health, and they tended to feel less fatigue, disability, and limitations in their social activities, although they had no differences in pain, physical discomfort, shortness of breath, or psychological well-being, compared to patients who did not participate in the program. Program participants did have fewer and shorter hospitalizations.⁹

Patients who have received diabetic education, either individually or in groups, have had better diabetic control than those who received no educational intervention. ¹⁰ Patients with mental illness, including schizophrenia and depression, have been shown to be responsive to efforts to get them actively involved in their own care. ¹¹ Pregnant young women who participated in group prenatal care that provided education and support had significantly lower rates of preterm birth and low-birth-weight infants than nonparticipating young women. ¹² Yet it must be recognized that interventions vary in their ability to achieve positive outcomes. ¹³

In sum, these findings serve to justify efforts to promote patient activation and engagement on consequentialist grounds, in addition to the deontological grounds that patient activation and engagement strategies demonstrate respect for persons.

Ethical Concerns And Stakeholder Responsibilities

Despite the promise, there also lurk ethical concerns. The first is that patient activation and engagement are sometimes used as a justification to encourage the use of technologies, or to build support for funding particular kinds of research, when there is not inherently a causal connection between the technology and actual patient empowerment.

Eric Juengst and colleagues have pointed out that this problem arises, for example, when certain kinds of genetic tests are directly marketed to consumers with the claim that undergoing such tests will enable patients to take more control of their health. If those tests identify increased risk for conditions for which there is no actionable remedy, the suggestion that getting tested will be empowering for patients is at best an overstatement, and at worst an erosion of actual patient empowerment and potentially a harm to well-being.¹⁴

Second, poverty and social inequality,^{4,15} as well as age, cognitive abilities, and other factors beyond a person's control, all influence the degree to which someone can take responsibility for his or her own health behavior. Therefore, expecting people to actively promote their own health is justified only when they have the capacity to be reasonably expected to do so and when others in society create a realistic opportunity for them to do so.

A third ethical concern arises as patient activation and engagement gain traction among health care leaders in hopes that healthier patients will lead to reduced health care costs. Stewardship of fiscal resources and a reduction in national health care costs are ethical imperatives worthy of endorsement. However, imposing financially burdensome penalties on ill patients who do not pursue opportunities for patient activation, predominantly in efforts to shift health care costs, would be ethically problematic.

There are ways to manage these ethical concerns if the key stakeholders address them. In this article we discuss the ethical issues that pertain to key stakeholders, and we identify responsibilities that patient activation and engagement should place on patients, clinicians, health care organizations and delivery systems, insurers and payers, and communities. These responsibilities are summarized in online Appendix Exhibit 1.¹⁶

The Patient

At the heart of the concept of respect for persons is an appreciation that people should have the right to determine their futures. The concept also implies an understanding that people differ dramatically in terms of their personal histories, their worldviews, and their health.

Some people will be markedly capable of self-efficacy—a belief in one's ability to succeed in a particular situation.¹⁷ Such people have had early childhood development and adult lives that offered opportunities to master tasks, they have witnessed others who have successfully completed tasks, and they have been persuaded by others of the strength of their personal abilities.¹⁷ At the other extreme will be people who not only lack the experiences that contribute to self-efficacy, but who also have experienced trauma, abuse, neglect, or deprivation, which undermine self-efficacy as well as self-respect.

Studies of the US population show marked variability in the degree of patient activation. Activation levels are especially low for people with low incomes, less education, and poor self-reported health, as well as Medicaid enrollees. ¹⁸ People who have had fewer opportunities to develop a sense of self-efficacy should receive greater support in anticipation of being active in their own health promotion. This additional support may include using peers as role models, teaching learning strategies, or providing options and choices.

Expectations should be individualized on several other grounds as well, such as cognitive ability and stage of development. The ethical conclusion is that people may be expected to actively promote their own health (Appendix Exhibit 1)¹⁶ and must be afforded the respect and opportunities that are necessary ingredients for doing so.

The Clinician

Perhaps it is not surprising that growing recognition of the importance of patient activation and engagement has occurred at the same time that the ethics of the clinician-patient relationship have been evolving. The relationship is increasingly perceived as a partnership to promote the patient's health. There is a focus on patient-centered care that implies that patients should be the judge of their care.¹⁵ There is attention to patient empowerment^{19–21}

that envisions the role of the patient as an active and fully participating partner on the health care team. 22

This shift in the conception of the clinician-patient relationship, along with the growing scientific evidence of the value of patient activation, has profound implications for the interaction between clinicians and patients. In activating their patients, clinicians should enable the patients to identify and explore their own goals; set up shared and realistic expectations with them; and provide adequate support structures for patients, so they can realistically achieve positive health outcomes.²³ Appendix Exhibit 2 contains an example of a dialogue between a patient and clinician that exemplifies a respectful interaction tailored to a patient's circumstances and preferences in online.¹⁶

An ethical quandary that arises with the growing awareness of the importance of a patient's active role in determining his or her health status concerns the degree to which patients should be held accountable for their behavior and health status in the course of clinical interactions.

Generally, holding someone accountable means that the person is blameworthy if he or she fails to live up to the responsibilities. Yet doctors have traditionally provided medical care without regard to the ability or willingness of patients to act on their own behalf, or to judgments about patients' moral character. If clinicians were to do otherwise, the most vulnerable people would face the double jeopardy of illness and blame—blame that may not be well founded.

The first reason for withholding such judgment is that the profound difference in the lived experiences of the clinician and the patient who is coping with illness means that the clinician can rarely fully appreciate the reality the patient is facing, even with great efforts to listen carefully and be understanding. ^{24,25}

A second reason for withholding judgment is an epistemic one, or one that relates to the clinician's limited knowledge of the causality of illness. To the extent that the factors determining a patient's health status are complex, a clinician cannot presume to know with certainty that a patient's health status is a consequence of the patient's personal actions. Thus, clinicians should seek to empower patients to cope effectively with illness and work together with patients to establish expectations that they will promote their own health. Nonetheless, clinicians should be cautious about subsequently judging their patients' behavior.

Exhibit 1 lists a variety of attitudes or activities that clinicians should avoid if they wish to activate patients.

Health Care Organizations And Delivery Systems

Health care delivery organizations have special obligations to build a culture supportive of patient activation and engagement. Such a culture is likely to result when leadership at the top of the organization endorses the importance of patient activation, when patients are

represented in the organizational boardroom, and when the infrastructure for getting patients involved in their care is put in place and brought to the public's attention.²⁶

Most important, health care organizations should be held accountable for ensuring that evidence-driven, state-of-the-art interventions for patient activation and engagement are employed. If the health system is developing new interventions, there should be a commitment— and adequate resources should be devoted—to studying their implementation and making continuous improvements.

Successful health care organizations will encourage leadership at various levels of the organization to use evidence-based patient activation strategies, where they exist. Such systems will also encourage experimentation with innovative forms of patient activation. One example is group sessions in which patients with the same chronic illness meet to share experiences and discuss how they can best support one another in adhering to guidelines for self-care.²⁷ Another is team delivery of care for chronic disease management, in which the patient is a key team member.¹⁹

Moreover, innovative organizational leaders will reach beyond the confines of their own organizations to collaborate with other health care entities and with entities outside the health care delivery sector to build more active opportunities for health promotion, so that people are less likely to require health care or to return to the health care delivery system as frequently. The leaders will coordinate with long-term care facilities, community-based organizations, schools, and civic leaders to enhance coordination of care, prevent exacerbations that result in additional hospitalizations, and build more active opportunities for disease prevention and health promotion.

Insurance And The Payment System

The current shift to performance-based reimbursement has the potential for profound consequences for patients and clinicians. If insurers impose penalties on patients who do not engage and who are judged to have worse health outcomes as a result, patients could face higher copayments and other burdensome financial consequences. Likewise, if clinicians do not demonstrate sufficient efforts to activate patients, they may face reduced reimbursements.

When insurers do offer incentives to promote patient activation, these incentives should be in keeping with the ethical justification that underlies patient activation and the goals of patient empowerment. The design of incentives that would thus be most appropriate would allow people enrolled in an insurance plan to select health goals for themselves and to set endpoints that are meaningful and achievable and that are likely to promote long-range health.

Under such an arrangement, a patient with hypertension who is obese might choose to aim for a weight-loss target; a patient with hypertension who is not obese might choose to aim for a target rate of blood pressure. Patients who are healthy might choose a target in health promotion, such as frequent participation in an exercise program. Insurance enrollees would be able to select the extent of the reward or penalty. At some reasonable interval, enrollees

could change their goals. Finally, enrollees should be able to opt out of such incentive programs.

How should insurers structure provider payments for patient activation? In general, providers should be reimbursed for offering interventions that promote patient empowerment and for outcomes that clinicians and patients have agreed upon and achieved. They should not be penalized when they have endeavored to activate a patient but the desired outcome is not achieved, if the outcome is dependent upon the actions of both the clinician and patient.

The Community

Health care plays only one part in determining health outcomes. There is growing evidence that communities and the many places where people spend their time working, learning, and congregating can promote health—and that when they do, there are statistically significant health benefits. ^{28,29} There are therefore responsibilities that leadership in each of these settings should assume. Community councils, school boards, employers, and religious leaders should participate in promoting the health and well-being of their constituents.

Online Appendix Exhibit 1 focuses on the obligations of these community leaders. ¹⁶ Fulfillment of these obligations will not only yield better health outcomes for individual patients. Civic leaders, employers, and school administrators who pursue engagement strategies are likely to find that the benefits redound to them in the form of healthier communities, more productive workplaces, and better-performing schools, respectively. ^{30,31}

Conclusion

Patient activation and engagement can improve the health of patients and do so in ways that are respectful and empowering. An ethically sound approach will place responsibilities and obligations not only on patients but also on clinicians, health care systems, payers, and civic leaders.

Acknowledgments

This work was funded in part by the intramural program of the National Institutes of Health. The authors thank Steve Pearson, Amina White, Peter Lichstein, and Elizabeth Gamble for their advice during the preparation of this article. The views expressed here are those of the authors and not necessarily a reflection of policies of the Department of Health and Human Services or the National Institutes of Health.

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16.

To access the Appendix, click on the Appendix link in the box to the right of the article online.

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Biographies



Marion Danis is the head of the Section on Ethics and Health Policy, Department of Bioethics, Clinical Center, National Institutes of Health.

In this month's *Health Affairs*, Marion Danis and Mildred Solomon explore ethical dimensions of patient engagement and activation. They observe that such strategies may be ethically justified in part because they are likely to produce better health and health care outcomes—but that they may also go ethically awry if assistance to patients isn't forthcoming, or if patients are unduly disadvantaged by punitive policies and practices. The authors offer examples of ethical approaches to patient activation that place obligations not only on patients but also on providers, payers, and communities.

Danis is the head of the Section on Ethics and Health Policy in the Department of Bioethics at the Clinical Center, National Institutes of Health. She also serves as chief of the Ethics Consultation Service at the center. Her research focuses on finding strategies for fair rationing of limited health care resources, involving the public in priority setting, and promoting strategies to address the social determinants of health to reduce health disparities.

Danis chaired the International Society on Priorities in Health Care and served on the Medicare Evidence Development Coverage Advisory Committee. She earned a medical degree from the University of Chicago.



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Solomon is the president and CEO of the Hastings Center, a bioethics research and policy institute. She is also a clinical professor of anaesthesia at Harvard Medical School, where she directs the Department of Global Health and Social Medicine's Fellowship in Medical Ethics.

Solomon conducts both normative and empirical research on a wide range of values questions and topics of moral uncertainty in health, health care, biomedical research, and public health. The primary focus of her scholarship has been on the ethics of end-of-life care for adults and children, organ transplantation, and research ethics. She is also an implementation scientist who has designed and evaluated numerous interventions aimed at empowering patients and promoting evidence-based practice. Solomon earned a doctorate in educational research methods and adult learning from Harvard University.

Exhibit 1Circumstances When The Pursuit Of Patient Activation Might Be Ethically Problematic

Circumstances	Ethical problems
When a strategy for patient-centered care and activation is used without regard to individual uniqueness	Expecting patients to engage in their care without understanding their unique circumstances and goals would be antithetical to patient-centered care; evidence shows that tailored interventions are effective ^a
When patient activation is pursued selectively or in a discriminatory manner, leaving out patients who might be difficult to work with for any number of reasons	Evidence shows that mentally ill patients who are often stigmatized can be actively involved in their care $^{\it b}$
When patient activation is prompted for purposes that a patient does not endorse	Negotiation should take place to resolve whether to pursue a health-related goal that a patient does not desire to pursue
When the goal of patient activation is beyond a patient's ability or means	Efforts should be made to provide the means if at all possible
When a patient activation approach is used in lieu of other warranted strategies to improve the patient's health	Although patient activation such as a patient-activated rapid-response system may reduce adverse outcomes, this strategy should not be used in lieu of other appropriate strategies to reduce adverse outcomes $^{\mathcal{C}}$
When patient engagement is used for purposes other than improvement of health and well-being	Strategies such as direct-to-consumer advertising, which may make patients aware of treatments for their medical conditions, are intended to market medications and should be recognized as such; sources of patient help and advice, such as self-help groups and noncommercial informational websites or other types of patient information, are preferable

Sources: Authors' analysis of Coulter A. Engaging communities for health improvement (Note 29 in text); Merzel C, et al. Reconsidering community-based health promotion (Note 30 in text); Williams LC, et al. Medical cost savings for web-based wellness program participants from employers engaged in health promotion activities (Note 31 in text).

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