

# Ethics of patient activation: exploring its relation to personal responsibility, autonomy and health disparities

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Received 9 March 2017

Revised 19 May 2017

Accepted 11 July 2017

Published Online First

3 August 2017

## ABSTRACT

Discussions of patient-centred care and patient autonomy in bioethics have tended to focus on the decision-making context and the process of obtaining informed consent, leaving open the question of how patients ought to be counselled in the daily maintenance of their health and management of chronic disease. Patient activation is an increasingly prominent counselling approach and measurement tool that aims to improve patients' confidence and skills in managing their own health conditions. The strategy, which has received little conceptual or ethical analysis, raises important questions about how clinicians ought to foster confidence and a sense of control in their patients without exposing them to blame, stigma and other harms. In this paper, we describe patient activation, discuss its relationship to personal responsibility, autonomy and health disparities, and make recommendations regarding its use and measurement.

## INTRODUCTION

There has been growing interest over the past four decades in facilitating patients' agency with respect to their medical care. Within the bioethics literature, attention has largely focused on achieving this through shared decision-making and robust informed consent processes.<sup>1–5</sup> However, many health conditions require patients to do more than authorise treatments—they demand daily self-management behaviours, such as following complex medication regimens, adopting new diets and exercise habits, monitoring health indicators and communicating effectively with healthcare providers.<sup>6–7</sup> Such conditions include diabetes, asthma, congestive heart failure, rheumatoid arthritis, chronic pain, obesity, and certain mental health conditions such as depression and anxiety.<sup>6–10</sup> For patients with these conditions, nearly all of the actions that influence their health outcomes occur in their daily lives *outside* of the healthcare setting, and the question of how they should be counselled in and prepared for these roles has not been adequately addressed by bioethicists.

In recent years, there has been increasing support for health education strategies that acknowledge patients as central figures in their care and increase patient empowerment.<sup>11–12</sup> However, approaches that aim to realise patient-centred care<sup>13</sup> face special ethical challenges in the context of conditions that require self-management and self-monitoring. Specifically, further emphasis on individual agency may overburden patients, both because they are *necessarily* in charge of implementing their

own treatments and because they are often viewed as being at fault for the adverse outcomes of their illnesses, leaving them particularly vulnerable to blame and stigma. Thus, a crucial question is how such approaches ought to be practised.

The aim of this paper is to address this question by examining the normative implications of one particular strategy for promoting patient self-management, which stands out as being widely adopted in clinical practice, research and healthcare systems evaluation. This approach, called *patient activation*, is used to measure and improve the extent to which patients have the confidence and skills they need to successfully manage a chronic illness.<sup>14–16</sup> Patient activation has a standardised definition and a validated measurement tool, but it has received little conceptual or ethical analysis. We begin the paper by defining patient activation and briefly describing how and why it is used. Then, we raise and address four ethical concerns that one might have about its use or measurement. Through discussing these worries, we clarify how activation relates to personal responsibility and autonomy and recommend ways in which the strategy can be practised in an ethically responsible way.

## UNDERSTANDING PATIENT ACTIVATION

### Its meaning and use

The term *patient activation* refers to both a state and a process. According to the broadly accepted definition, originally proposed by Judith Hibbard<sup>14</sup> and colleagues, an activated patient has the confidence, knowledge and skills required to manage her own chronic illness in a manner that improves her health. Activation is considered to have four progressive stages: (1) the patient believes she is responsible for her own health and feels as though she can influence it; (2) she knows what is required to manage her condition effectively; (3) she has the skills and behaviours necessary for implementing this knowledge; and (4) she is able to self-manage under stress. Interventions that promote activation are personalised, meeting patients at their present stages of development and providing targeted support.<sup>15</sup>

An individual's level of activation is evaluated by the Patient Activation Measure (PAM)—a 13-item questionnaire that was designed with input from experts in the treatment of chronic disease, patients with experience managing one or more conditions, and the literature on self-care and self-management.<sup>14</sup> The measurement tool has since been validated for use in numerous languages, cultures and



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**To cite:** Gibert SH,  
DeGrazia D, Danis M.  
*J Med Ethics*  
2017;**43**:670–675.

medical populations.<sup>16</sup> The PAM includes questions about the patient's knowledge of her prescribed medications and the nature and causes of her condition, her ability to problem-solve in new situations, and her confidence in the advice of her healthcare providers, among other topics. The items are not condition-specific and do not ask whether one actually engages in successful self-management or preventive behaviours.<sup>15</sup> As such, patients can be fully activated without optimising their health, and activation does not demand that healthful behaviour be pursued above other interests that promote the patient's well-being.

Patient activation is presently used in three ways. First, PAM scores help clinicians anticipate the type of discussion and guidance a patient may benefit from before an appointment begins, and the questions associated with the PAM provide a structure for conversations about health behaviour.<sup>17</sup> Imagine that a patient comes in for an appointment after having had a heart attack. Using the activation questions as a guide, a clinician might explore how this patient has been coping with recent events and how he feels about the lifestyle changes he may need to make in order to prevent another attack. If the patient already feels confident and motivated, then the clinician may provide more detailed information or may help him develop a structured diet and exercise plan. If the patient feels overwhelmed or powerless, then a clinician may devote time to understanding the origins of this feeling and will help him determine some manageable tasks that can reduce his risk level while building his confidence. Strictly speaking, there is no evidence that patients must progress through the stages of activation in order, but those who score at the low end of the PAM scale are likely to also score poorly on questions corresponding to early stages of activation.<sup>15</sup> Thus, activation is typically framed as an ordered process, through which clinicians can help patients advance.

Activation scores can also be incorporated into electronic records and used to structure patient care. For example, activation scores can inform the amount of guidance provided during discharge and follow-up, as well as the matching of patients with clinical care teams and support groups.<sup>16 17</sup> A third use for the PAM is in research and evaluation. The improvement of patient activation scores over time can serve as a patient-centred outcomes measure and a quality improvement measure, and advocates of the approach envision more widespread use of the PAM in research and evaluation for public health interventions in the future.<sup>17</sup>

### Motivating patient activation

Healthcare organisations that employ the PAM do so primarily because evidence shows that patients with high PAM scores have better health outcomes, lower costs and greater patient satisfaction.<sup>16</sup> While there has been little research on the relationship between system-wide practices and their expected benefits, there is evidence that increasing an individual's level of activation leads to desirable health outcomes. Numerous cross-sectional and prospective studies in the USA and abroad have demonstrated that patient activation is associated with greater engagement in preventive health behaviours, avoidance of unhealthy behaviours, better control of symptoms, greater health literacy and disease-specific knowledge, and fewer emergency department visits and hospitalisations, after relevant factors such as socioeconomic standing, insurance status and disease severity are controlled for.<sup>15 18 19</sup> Activated adult patients with chronic conditions tend to have higher patient satisfaction scores, quality-of-life scores and physical and mental functional status scores than those with low activation—findings that persist after

adjustments are made for patient demographics, disease characteristics and geographic location.<sup>20</sup>

In addition to promoting good health outcomes, patient activation and related strategies are said to be consonant with the principle of respect for persons, in that they aim to enhance patients' capacities for self-determination.<sup>21</sup> This is not to say that patient interactions not involving activation violate this principle, but rather to point out that activation enhances and respects patient autonomy in a way that more traditional compliance-based strategies do not.<sup>22</sup> There is more to be said about the relationship between patient activation and autonomy, so we return to this subject in a later section.

### FOUR WORRIES ABOUT PATIENT ACTIVATION

In the remainder of the paper, we raise and respond to the four most serious ethical objections that we anticipate against patient activation, before concluding. Addressing these objections reveals ways in which clinicians and patients ought to approach issues of personal responsibility, autonomy and health disparities when practising activation and related strategies.

#### Worry 1: it is unclear what type of responsibility activation asks patients to accept

The first concern we anticipate is that activation requires patients to have a sense of control and responsibility for their health behaviours, but it is not clear exactly what this means or what obligations this places on patients. This worry arises in light of the first stage of activation, which encourages patients to agree with the following two claims: (1) 'When all is said and done, I am the person who is responsible for managing my health condition' and (2) 'Taking an active role in my own health care is the most important factor in determining my health and ability to function' (Hibbard *et al*<sup>15</sup> p. 1923). In this section, we consider what sense of responsibility activation should ask patients to accept and what degree of control activated patients should consider themselves to have. To begin, we consider the notion that activated patients accept some kind of moral responsibility for their health behaviours. Then, we argue that patient activation should be understood as encouraging something other than moral responsibility, and we explain the consequences of this position.

Perhaps the most natural reading of the PAM is that the term 'responsible' means not just *causally* responsible, but *morally* responsible, so activation asks patients to believe they are morally responsible for their health behaviours. Before proceeding, note that activation does *not* require patients to accept responsibility for *being* ill or for continuing to be ill after treatment, but asks them only to accept responsibility for their self-management actions.<sup>15</sup> In general, what it means for an agent to be morally responsible for her behaviour is that this behaviour is attributable to her in such a way that makes her eligible for moral appraisal (such as praise and blame) on its basis.<sup>23–25</sup> For instance, if Maya donates to charity, she may be open to praise; if she cheats on an exam, she may be eligible for blame. This sense of moral responsibility is what TM Scanlon and others call *responsibility as attributability*.<sup>23 25</sup> Certain conditions tend to excuse individuals from moral responsibility in this sense: if we find that Maya has cheated on her exam by accident, or during a fit of sleepwalking, or that she has been coerced into cheating, we would tend to revise our judgment that she is responsible. However, there is disagreement over what exactly makes agents' actions attributable to them. Some hold that the agent must have exercised control over the action and the conditions that brought it

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about.<sup>26</sup> Others require that an agent can reflect on and identify with her behaviour,<sup>27</sup> or that her behaviour issues from a will that reflects her true self<sup>28–30</sup> or from a mechanism that is responsive to a range of rational considerations,<sup>31</sup> or that her behaviour reflects her evaluative judgments.<sup>25</sup> <sup>i</sup> It is neither our intention to give an exhaustive list of accounts of moral responsibility, nor to defend any particular view, but rather to illustrate a range of options in a way that will prove helpful later on.

One way in which we might view patient activation, then, is as a motivational approach that encourages patients to think of themselves as morally responsible for their health behaviour in the attributability sense. Importantly, this interpretation would *not* entail that it is appropriate for others to blame activated patients if they fail to manage their health successfully; nor would it imply that clinicians should attempt to motivate patients by blaming or stigmatising them. A judgment of attributability is a theoretical judgment of whether an agent's action reflects her true self or is a product of her rational capacities. It is distinct from the judgment of whether it is justified for someone else to *hold* that individual responsible through reactive attitudes or through reward or punishment. In other words, even if an individual is morally responsible for her behaviour in the attributability sense, it may be inappropriate to blame her.<sup>23 32 33</sup> Other factors play a role in determining whether blaming her is justified. For instance, we should not blame individuals for actions that are not morally wrong.<sup>32</sup> Even if someone has in fact done wrong and is morally responsible, we should not blame her if we are in a poor epistemic position to judge whether she is morally responsible, or if we are unfairly prone to blaming her or people we perceive as being like her. Both of these considerations are relevant in the context of patient activation. First, it is not clear that failing to take an active role in one's health is morally wrong. Second, as Danis and Solomon<sup>21</sup> argue, clinicians have limited information about the circumstances that influence their patients' health and health behaviours, even when they do their best to understand them. Furthermore, the role of clinicians is to provide medical assistance to patients regardless of their values, abilities to pay or abilities to take active roles in care. Thus, it is inappropriate for clinicians to blame patients if they do not carry out self-management behaviour as planned.<sup>ii</sup>

We agree with Danis and Solomon that clinicians and others ought not blame or penalise patients if they have poor health or lack effective health behaviour. Still, there are at least two approaches to patient activation that are consistent with this perspective. One is for clinicians to encourage patients to accept moral responsibility for their health behaviour in the *attributability* sense, and another is to refrain from assigning moral responsibility entirely. We support the latter approach: patient activation should be practised *without* encouraging patients to view themselves as morally responsible for their health behaviour, and those involved in activation can and should remain agnostic about whether patients' health behaviours are attributable to them. Accordingly, the first step of activation should encourage the patient not to accept moral responsibility, but rather to:

1. value her health, all other things being equal, and
2. strategically adopt an attitude of self-efficacy with respect to future health behaviours.

The first of these conditions asks the patient to value the health benefits that have been shown to result from an increased activation level. As we will explain in a later section, this does not mean that patients must value improvements in health above other pursuits, but simply means that they must be motivated by the prospect of good health outcomes. The second condition encourages the patient to make a strategic choice to view her future health behaviours as actions she can cause or control.

Having a sense of confidence or empowerment is known to be integral to activation and related strategies.<sup>21</sup> However, the sense of self-efficacy we advocate is to be explicitly contrasted with the belief that one is morally responsible for one's health behaviour. An agent can look towards a future health-related action and recognise that it is likely to be influenced by habits and character traits she wishes she did not have, yet still may take an optimistic stance about her capacity to influence it. To this end, clinicians and patients should discuss and explore the *causal* mechanisms of patients' conditions, and clinicians should provide an accurate understanding of the role that behaviour plays in their health status. These discussions can be helpful and even necessary to making and adjusting successful plans for self-management. Such discussions should recognise the ways in which external factors influence patients' behaviours and should encourage in the patient a sense of optimism as a pragmatic tactic, based on the belief that it will serve her well. If the patient then fails to carry out her planned behaviour, the activated patient will have the self-confidence to renew her optimism and direct it towards future actions again, rather than blame herself for past ones. Of course, this process is not expected to be psychologically easy, nor is it likely to continue indefinitely if someone repeatedly adopts a sense of self-efficacy towards goals she is unlikely to achieve. We address instances in which this process is not feasible for circumstantial reasons in the next section.

To clarify, our recommended approach concerns the way in which clinicians discuss and foster activation, and not the way in which the PAM is worded. The PAM is a validated measurement tool and must be phrased with attention to multiple factors. Our position has to do primarily with the conversations that occur between clinicians and patients, relating to the first stage of activation. Our account is successful in three ways. First, it coheres with what we take to be the aim of patient activation in a way that a view based on moral responsibility does not. In motivating patients to take active roles in their care, clinicians presumably aim to help them self-manage *not* out of a sense of duty or fear of guilt, but rather with the hope that it will benefit them. Second, our account is philosophically appealing because it allows those practising activation to remain agnostic about whether patients are morally responsible for their health behaviours. Many accounts of moral responsibility would not regard health-related actions—especially those that affect health negatively—as attributable to agents. For example, an agent's choice to consume highly processed food or to skip a dose of medication typically occurs out of habit, is often not reflected on and frequently does not cohere with the agent's true self or higher order values. In order to consider patients morally responsible for their health behaviours, then, one must operate on a lenient view of moral responsibility. Such a view is likely to categorise actions we tend to think we are not responsible for, such as addictive behaviours and those we do not endorse, as attributable to agents. Third, our interpretation of activation allows clinicians and patients to pursue the benefits of activation interventions without opening

<sup>i</sup>The conditions of moral responsibility identified here are what scholars have also called conditions of free agency or autonomous action.

<sup>ii</sup>We would not say categorically that such individuals should never be criticised. Individuals who ignore their health and in so doing put the projects or well-being of others at risk may warrant criticism in some circumstances, but such criticism should come from those in positions of authority regarding these projects, not from healthcare providers. Additionally, we would not say that clinicians should have no expectations or make no demands whatsoever, but to the extent possible they should give patients the benefit of the doubt.

patients, even theoretically, to moral appraisal, which could expose them to certain harms. This point is explored further in the next section.

### Worry 2: activation sets the patient up for harmful consequences

The second worry we anticipate is that activation makes patients vulnerable to certain harms. There are two concerns in this vein: first, that increasing an individual's activation level could lead her to acquire a sense of hopelessness regarding her health behaviour under certain circumstances; and second, that endorsing activation as a strategy for addressing health problems could validate or perpetuate attitudes that expose patients with chronic conditions to blame, stigma and the denial of healthcare resources.

As suggested in the previous section, individuals who become more activated may be exposed to the psychological harm of learnt hopelessness if they repeatedly adopt attitudes of confidence and self-efficacy towards behaviours they are unlikely to achieve. We make two recommendations in response to this worry. First, patients should not be encouraged to believe that their behaviour is necessarily the *most* important factor influencing their health, as the PAM currently suggests.<sup>15</sup> While it is often appropriate to convince patients that health behaviour is important, the degree to which behaviour matters will depend on the particular health condition and the patient's circumstances. Second, patients should not be encouraged to adopt a sense of control towards too many goals that they are unlikely to achieve. To the extent possible, clinicians should determine to what degree a patient is likely to benefit from a more active role, based on her circumstances and experiences. Clinicians should arrive, in consultation with patients, at plans for small initial changes that are contextually appropriate. One might object that a clinician is never in a good position to judge whether her patient will be able to control her future health-related actions, just as she is never in a good position to judge whether her patient is responsible for them. However, this is not as great a challenge here because the clinician does not need to know that her patient has sufficient control over every action she plans to perform. Rather, she must predict that her patient will succeed with respect to more behaviour changes, or more important ones, than she will struggle with. In this way, the focus of patient activation is on bringing the patient to an overall better position in the future, rather than on avoiding all goals that she is unlikely to achieve.

Patients who truly do not stand to benefit from adopting a sense of self-efficacy regarding their health behaviours should nevertheless receive support. As Danis and Solomon<sup>21</sup> argue, clinicians and others take on certain obligations in promoting patient activation. There are many paths physicians and healthcare systems can take to ensure patients have enough support to implement at least some beneficial behaviour changes, such as offering basic cooking classes, monitored exercise sessions and social support services. We return to the issue of providing support for these patients in a later section.

A separate but related concern is that promoting strategies like patient activation, which target individual behaviour, may draw attention away from efforts to address the social determinants of health<sup>34</sup> and may increase the stigmatisation of ill individuals by reinforcing the notion that individual behaviour is largely to blame for poor health outcomes.<sup>35</sup> This issue must be addressed both within the practice of activation and outside it. Clinicians and others employing patient activation must be aware of the social and economic determinants of health behaviour and of

activation itself.<sup>21 36</sup> There is a compelling body of evidence demonstrating that social and economic factors play a large role in determining both health outcomes and health behaviours and that changes in social policy can improve the health of populations.<sup>37–41</sup> Still, health can be promoted at multiple levels, and activation is something that patients, clinicians and healthcare organisations can pursue to improve patients' lives *within* their present roles. As such, they should view themselves as working to improve health outcomes and fostering patient autonomy in non-ideal circumstances. Meanwhile, the possibility that patient activation will perpetuate the attitude that individuals are to blame for their health conditions is concerning. Our interpretation of the relationship between patient activation and responsibility is meant to minimise this risk, as it encourages patients, clinicians and others to suspend judgments about patients' personal responsibility and control. However, it is possible that retributive attitudes will persist despite efforts to suspend evaluations of moral responsibility.<sup>42</sup> Thus, while patient activation need not perpetuate unhelpful and inappropriate attitudes towards ill individuals, it will not necessarily reduce their prevalence either.

### Worry 3: activation may diminish autonomy for some patients

Earlier in the paper, we followed Danis and Solomon<sup>21</sup> in asserting that patient activation has the potential to support autonomy. Activation can enhance patients' capacity for autonomous action by helping them identify how they want to manage their conditions and by helping them achieve this in a way consistent with their values. Still, there are two ways in which patient activation risks coming into conflict with autonomy: first, activation may fail to enhance patients' capacity for self-determination if clinicians adopt too narrow a conception of what it means to respect autonomy; second, activation may diminish autonomy in some patients because it asks them to behave in a way that corresponds with a particular value—that of promoting their own good health—that they might not hold (however unlikely this may be).

Consider first that activation may fall short of its potential to support autonomy if clinicians construe the principle of respect for autonomy too narrowly. Now, there are at least two senses in which an intervention can be said to agree with the principle of respect for autonomy. In one sense, an intervention might respect an agent's authority or right to self-govern, which we presume belongs to at least all competent adults on the grounds that they have a certain threshold level of capacity for autonomous action.<sup>43 44</sup> An intervention respects autonomy in this sense by *not limiting* the ways in which an individual chooses to live and by *not interfering* with the realisation of her values.<sup>27 45</sup> In another sense, an intervention might promote an agent's capacity to act autonomously by placing her in a context that allows her to develop this capacity, providing relevant information, helping her appreciate its significance, helping her clarify her values and priorities and the like.<sup>45</sup> Both senses of autonomy have been affirmed in the bioethics literature.<sup>45</sup> However, practical applications of the principle of respect for autonomy have been criticised for overemphasising individuals' negative rights to be free of controlling constraint and for underemphasising individuals' positive rights to be given opportunities to develop their capacities for autonomous action.<sup>46–48</sup> Thus, it is important for clinicians and others to interpret respect for autonomy not purely as an obligation of non-interference. Just as patient-centred care in decision-making contexts should not leave patients to make decisions alone,<sup>47</sup> patient activation should not deprive patients of clinicians' support. Rather, it should entail clinicians



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actively collaborating with patients to select, plan and facilitate their self-management behaviour.

A second concern is that patient activation risks diminishing autonomy for some patients because it asks them to value their own health, all other things being equal, and some individuals may not hold this value. Before proceeding, note that activation does *not* push patients to value health above all else. One can be fully activated and at the same time choose to prioritise non-health-related values over health-related ones to an extent. For instance, an excellent chef who is a diabetic may need to taste the food she prepares, despite its conflicting with her weight control. An avid soccer player may wish to ignore advice to rest his injured knee. Activation should be viewed as requiring that patients have the confidence, knowledge and skills to be able to manage their conditions—not that they carry this out in a way that optimises health to the exclusion of other concerns.<sup>14</sup> As such, the concept of patient activation should not be interpreted as dictating how patients prioritise health in relation to other projects and goals in their lives. If a patient decides to take a less active role in her self-management or chooses to prioritise other aims in life, even though she would likely benefit in terms of health gains, a clinician might help her deliberate about her priorities but should not dictate or judge her priorities. To do so would be disrespectful of her autonomy.

For most patients, then, the concern that patient activation diminishes autonomy will be irrelevant as long as the strategy is not misinterpreted. Reasonable people value their health and happiness, all other things being equal. Those patients who do value taking an active role in their health, when they are likely to benefit from doing so, will experience no diminished autonomy from activation, and those who would *not* benefit from taking an active role will not be encouraged to or, preferably, will be supported enough so that their taking an active role will become beneficial. However, there could conceivably be a group of patients who stand to benefit from activation but adamantly refuse it, perhaps because they value a certain kind of spontaneity or because they prioritise the health of another person over their own. A parent, for example, might give her own health low priority as compared with the health of her child and may thus decide against taking an active role in her health promotion at a given time. Insofar as competent patients are in positions such as these, their rights to govern their lives according to their own values should be respected, and they should not be pushed to become activated. In sum, if activation is not forced on anyone, then efforts to encourage activation will be, at most, slightly paternalistic towards a small group of patients.

It seems that patient activation is currently practised in a way that mitigates these two worries about autonomy. Advocates of the approach stress that it is meant to support a shift in culture, away from clinicians giving information and expecting patients to comply with recommendations, and towards a model in which clinicians gain a deeper understanding of each patient's goals, collaborate with patients and acknowledge patients' central roles in their care.<sup>17</sup> Still, it is essential to highlight the role of patient autonomy in activation, since there is potential for the approach to be misunderstood and misused such that it isolates patients or forces them to comply with clinician recommendations.

#### Worry 4: patient activation may worsen health disparities

The fourth worry to be addressed here is that patient activation might worsen health disparities. This could occur in two ways. First, those who are already more highly activated may be more likely to benefit from activation interventions than those who score low on the scale. In theory, patient activation

accommodates patients' present activation levels and thus is just as effective for the highly activated as for the poorly activated.<sup>14</sup> However, it may be less demanding to help someone maintain healthy behaviour than to build someone's self-efficacy, confidence and skills from an initially low level, so those who are already better off may benefit more. This is not necessarily morally problematic, since activation is a non-zero-sum practice. That is, one person's becoming more activated does not prevent another person from simultaneously becoming more activated. If there is an injustice, it lies in the background conditions that lead to some benefiting less than others, rather than in the practice of making activation available. In theory, then, any obligation to remedy these background conditions is distinct from those stemming from patient activation. However, adopting activation as a tool costs healthcare systems some resources in the short term,<sup>17</sup> and if done in lieu of other approaches might benefit one group of patients over another. Thus, promoting patient activation might involve selecting certain patients to be left out of health benefits—those patients who are the least activated. In light of this, patient activation should be pursued with a commitment to distribute resources and services preferentially towards those who are socioeconomically disadvantaged. This process could be aided by redirecting the resources that a health system saves through activation approaches in the long run towards disadvantaged individuals. Some ways of supporting this group of patients include holding classes for people beginning new diets or medication plans, providing monitored exercise opportunities early during treatment, providing transportation or extended hours and providing social support services. Danis and Solomon<sup>21</sup> provide further discussion of how clinicians, insurers and the community can support activation efforts.

The second way in which activation could worsen health disparities is by imposing more risks on those with low activation scores than on those with high activation scores. Those with low activation tend to have lower incomes, less education and more precarious health insurance status than those with high activation.<sup>36</sup> These disadvantages could make them more vulnerable to blame, stigma and learnt hopelessness. If they are more vulnerable in these ways, this problem is inherent to the practice of activation. As such, the risks associated with activation must be minimised overall, as described in the section regarding worry 2, and those with lower activation scores must be given more support by the institution employing activation. Some systems already adopt this practice, using PAM scores to identify those who should receive more experienced staff, more time and more support after discharge from the hospital.<sup>16</sup> Furthermore, advocates of patient activation are committed to reducing health disparities and present this as one of three main goals of implementing the PAM, along with improving patient self-management and delivering outcomes-based care.<sup>17</sup> We recommend that this goal continue to be emphasised and built into the practice of activation.

#### CONCLUSION

In this paper, we have presented an overview of patient activation and the rationale for its employment. We have also posed and addressed the four most serious ethical challenges that the approach faces. In doing so, we have defended an account of the relationship between patient activation and personal responsibility and have clarified the meaning and place of autonomy in activation. The argument has revealed several lessons about how patient activation and related strategies should be practised. First, those who employ patient

activation ought to suspend judgments about whether patients are morally responsible for their self-management behaviours so that they can emphasise the benefits of activation without instilling fear of blame, stigma or poor health outcomes. Second, activation should involve an effort to understand the circumstances within which patients operate, so that they are not encouraged to adopt a sense of self-efficacy and control when it is too risky to do so. Third, activation should provide opportunities for patients to develop their capacities for self-determination and should seek to promote their goals, rather than imposing values or prioritisations of particular values. Fourth, patients who are unlikely to benefit from activation due to their circumstances should be provided with extra support when this support might lead to greater success. Lastly, activation should be implemented in a fair manner, such that those with the lowest activation scores are provided with a high level of attention and resources. We hold that if patient activation is understood and applied in this way, it has great potential for promoting positive health outcomes and for respecting and enhancing patient autonomy.

**Acknowledgements** The authors wish to thank Jonathan Pugh, Joseph Millum, Robert Steel and two anonymous reviewers for their insightful comments on earlier drafts of this paper.

**Contributors** SHG drafted the manuscript. SHG, DD and MD made substantial contributions to the conception of the work and to critical revisions for important intellectual content. SHG, DD and MD gave final approval of the version to be published.

**Disclaimer** The opinions expressed herein are the authors' and do not reflect the policies and positions of the National Institutes of Health, the US Public Health Service, or the US Department of Health and Human Services.

**Competing interests** None declared.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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# Ethics of patient activation: exploring its relation to personal responsibility, autonomy and health disparities

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*J Med Ethics* 2017 43: 670-675 originally published online August 3, 2017  
doi: 10.1136/medethics-2017-104260

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