Dilemmas of Representation: Patient Engagement in Health Professions Education

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Abstract

The role of the patient in bedside teaching has long been a matter of consideration in health professions education. Recent iterations of patient engagement include patients as storytellers, members of curriculum planning committees, guest lecturers, and health mentors. While these forms of patient engagement are reported to have many benefits for learners, educators, and the patients themselves, there is concern that such programs may not be representative of the diversity of patients that health care professionals will encounter throughout their careers. This problem of representation has vexed not only educators but also sociologists and political scientists studying patients' and the public's involvement in arenas such as health services research, policy, and organizational design.

In this Perspective, the authors build on these sociological and political science approaches to expand our understanding of the problem of representation in patient engagement. In doing so, the authors' reconfiguration of the problem sheds new light on the dilemma of representation. They argue for an understanding of representation that not only is inclusive of *who* is being represented but that also takes seriously *what* is being represented, *how*, and *why*. This argument has implications for educators, learners, administrators, and patient participants.

The education of health professionals cannot be undertaken without the existence of patients. Long has this truism held, most often described in the construction of patients as objects of learning at the bedside[1] or the use of patients in classrooms or lecture halls to demonstrate physical examination findings or interesting aspects of a clinical "case." More recently, a different wave of patient engagement in health professions education has gained popularity.[2,3] In what Regan de Bere and Nunn[4] call a new pedagogy, patient engagement in health professions education reflects a demand for current or former patients to be involved as *active agents* in the design and delivery of formal instruction at all stages of the educational continuum. This includes having patients participating in curriculum planning and delivery, learner assessment, and as representatives with decision-making power in admission processes and hiring practices. The rationale underlying most of these forms of engagement is that incorporating patients' perspectives will contribute to learning experiences that are more patient centered and will result in trainees who are more compassionate and humanistic. Each of the different forms of patient engagement—such as patients as teaching cases, as narrators,[5] as health mentors,[6] and as decision makers—has its own body of literature, rationale, argument of efficacy, and concern about evaluation.[4,6–9] Despite the potential differences between these various practices of patient engagement, they each share a common concern: the dilemma of patient representation.

The dilemma of patient representation is often described in light of a pervading question: Are the voices of the patients being selected by patient engagement programs sufficiently diverse to represent the complex cultural, social, and economic complexions of contemporary society? There is a growing worry that the answer is no. Authors have critiqued the tendency of patient engagement programs to be populated by white, affluent, older adults.[10,11] As a result, there is widely held concern that well-intentioned patient engagement programs risk creating unintended effects. If such programs represent only a select demographic group, there is a risk that the concerns and priorities of only a privileged few will be taken to reflect the needs of all. This situation may have the effect of silencing the voices of those patients who are not reached through standard recruitment efforts. In doing so, these patient engagement programs may inadvertently reproduce structures of power and privilege in health care, as the concerns of the more powerful are most likely to be heard by educators and decision makers.[12] Furthermore, by excluding many groups through limited representation, patient engagement activities may further delegitimize marginalized perspectives, potentially reinforcing stereotypes in the minds of medical trainees that may persist unchanged throughout their medical careers.[11] Often, these critiques of representation focus on technical problems of patient engagement—for instance, how does one reach the hard-to-reach communities and represent them in patient engagement programs?

In this Perspective, we elaborate on these dilemmas of representation. We do so by acknowledging the concerns with the technical aspects of patient recruitment, but we also question the nature of the

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dilemma of representation itself. Drawing on literature in sociology and political science, as well as our own experiences in creating patient engagement programs in collaboration with individual patients, families, and patient groups, we suggest that aspects of the dilemma of representation are anchored in how we understand representation as a concept. We also explore questions about how patient engagement might be constructed, what is being represented in these constructions—and most important—the many reasons why patient engagement might be incorporated within health professions education at all. The overall aim of this essay is to offer emerging insights and to invite further conversation about fundamental concepts informing patient engagement efforts.

Dilemmas of Representation

Dilemma 1: How patients are recruited influences who participates

Critiques of patient representation are frequently anchored in the ways in which patients are recruited to participate in programs and how the programs themselves are constructed. Here, we challenge the organization-centric nature of many patient engagement programs, where health care systems create programs that stage events or hold meetings at their sites, at inconvenient times for the patients, in imposing rooms, with hosts of people that are socialized into particular ways of relating. The argument underlying this form of critique is that the organizations themselves are creating burdens associated with the practices of engagement (including time spent, costs incurred, and effort expended) and that these burdens may not be distributed equally across a range of patients. In framing these problems of engagement as part of faulty or inadequate organizational techniques, the solutions generated become ones of outreach: more inclusive designs and more flexible times for engagement activities. This emphasis on outreach has given birth to a science of "recruitmentology"[13]—that is, creating more and more strategies for attempting to reach the "hard-to-reach."[14]

Important work has been done that attends to these strategies of recruitment in health professions education.[4] Further

work seeks to match potential participants to the aims of the engagement exercise. It stands to reason that an education activity that seeks to teach physical examination skills might require a different form of patient participation than an exercise that invites patients to share their experiences as a way to, ultimately, disrupt societally entrenched forms of stigma. Typologies of patient "types"—such as that offered by Williamson[15]—suggest ways that educators might find the "right" patient for a particular kind of engagement activity. Specifically, Williamson's[15] typology draws attention to different forms of knowledge that may be held by an individual, by patient groups that are united through common experiences, or by patient groups that are actively constructed around particular advocacy aims.

In summary, nuanced practices of patient recruitment attend to who is being invited, for what purpose, and how such invitations might be offered to ensure full and meaningful participation. However, it is possible that despite the best efforts of educators and the most careful attempts at "matching" patients to programs, individual patient volunteers participating in these engagement exercises may still have difficulty establishing their credibility with trainees, other educators, and program evaluators. Thus, the dilemma of representation persists beyond these recruitment "best practices."

Dilemma 2: Choosing among multiple forms of representation

In this section, we set aside practical considerations regarding practices of patient recruitment to look at patient engagement from a more theoretical perspective, to explore how representation is implicitly and explicitly understood to work in various patient engagement programs. This theoretical exploration is necessary to shed light on the ultimate aim: How might we continue to do patient engagement well in health professions education? We examine assumptions about the nature of representation that are currently operating in patient engagement programs, and focus on three different types of representation and their possible applications in the context of patient engagement: democratic, statistical, and symbolic. Each has its own features, goals, and methods that may contribute to, but

may also complicate, the understanding of the "right" type of patient to include in health care and health-education-related activities.

Democratic representation. Often, it is a democratic image of representation that is implicitly held by the various stakeholders within patient engagement programs. When patient engagement programs are predicated on notions of democracy, we hear rationales for engagement rooted in democratic principles of rights, responsibilities, and power sharing. For example, the notion that patient engagement *should* be done because patients are the ultimate stakeholders in health professions education—and therefore should have the right to influence what should be taught and by whom—is a rationale anchored in the rights of patients and members of the public. This rationale lends itself to a democratic understanding of engagement.

In democratic societies, principles of representation are met through practices of nomination and election. Thus, the implicit model of representation at play in these kinds of programs implies representation achieved through particular processes. It is through these processes of nomination and election that an individual is granted the right to speak on behalf of others.[16] However, patient engagement programs cannot replicate this process in the selection of "representatives." Given the need for confidentiality as well as a whole host of logistical challenges, processes of nomination and election are impossible to sustain in groups that can best be thought of as categorical, not collective. That is, a person requiring health care may be unambiguously and temporarily categorized as a "patient," but a group of individuals who have required health care are not intrinsically organized together according to principles of collectivism.[17] Even in the presence of organized patient groups, it is difficult to locate an identifiable collective of patients that could be said to reliably reflect the entire patient group. The result is that patient engagement programs may be presumed to have a weak form of democratic representation at play.

Statistical representation. Another form of representation operating within patient engagement programs is the

notion of statistical representation. This form is familiar to the field of evidence-based practice and relies on knowledge that can be generated through surveys of large groups. This is a form of descriptive representation and determines the degree to which a representative could be considered similar to the "average" of that to be represented.[18] Here, the hope is that through sufficiently sophisticated data collection tools and large-enough sample sizes, we can approximate some true understanding of what patients want and need from their health care systems and from health professions educators.

However, this form of representation runs into a different kind of conceptual trouble within patient engagement programs. When notions of statistical representation are translated into recruitment practices—whom we should invite to participate in what programs— thorny questions of diversity emerge. Just what *kind of diversity* matters for what kind of exercise? Diversity in terms of race/ethnicity? Gender? Socioeconomic status? Disease type? Age? Educational level? There is a risk that individuals who wish to participate will be excluded or invalidated if they are not considered to add to the representative complexion of the patient participant pool.[11]

This implicit notion of representation— that a person can somehow represent the "average" of that to be represented— confronts another dilemma within patient engagement programs. Learmonth et al[19] refer to this as the "Catch-22" of patient engagement: A patient participant is invited into a program with the implicit assumption that he or she will be able to represent the "average" experience for the involved patient group. However, to participate effectively in the engagement exercise, the patient participant must usually possess particular skills, not the least of which includes being able to participate in the activity, to understand the aims of the exercise, and to navigate the various complexities of his or her role. Upon demonstrating the skills required to be effective, he or she runs the risk of no longer being considered "average." Thus, to be effective is to no longer be representative in the descriptive sense.

In short, conceptualizations of representation rooted in democratic principles and statistical notions each create their own problems and dilemmas in the practice of patient engagement. However, there is another, implicit frame of representation that is possible to consider. This third frame is best considered as symbolic representation.[16]

Symbolic representation. Whereas democratic representation may be understood in terms of formal processes used to designate representatives, and descriptive, or statistical, representation may be understood in terms of the tools used to generate a sense of the "average" object or individual being represented, symbolic representation is best understood through the metaphor of art.[16] Echoed in the Platonic notion of *mimesis*, art has always had the function of *representing something*, of bringing something that was previously absent into physical presence. However, especially in modern art, there is no associated assumption of fidelity to that representation. Abstract art is still art. What is being represented is instead a feeling, an impression, an experience, a concept, or a subjective belief. Herein lies the substantive difference between symbolic representation, on the one hand, and the other conceptualizations of representation (democratic, statistical) that seem to be implicitly fueling patient engagement programs on the other. Art does not need to be statistically or democratically—or even realistically— representative of its object for the viewer to be moved, changed, or otherwise inspired. Because of this quality, it is the *authenticity* of feeling or experience that is to be represented, rather than *fidelity* to some democratic, statistical, or mimetic norm. What is represented in symbolic representation is a unique, individual perspective. No attempt is made to argue that a story told by a patient is "typical" or "average" of all stories by all patients; rather, each narrative represents one story from one patient on a spectrum of human experiences related to illness.

Educators who take up symbolic notions of representation are careful to draw attention to the ways in which patients' narratives inform critical thinking, humanism, compassion, and empathy without making any claims about the generalizability of the narrative itself.[20] Instead, the use of narrative becomes one way to sensitize trainees to the rich tapestry of human experience—the varieties and possibilities of being—that

might accompany a particular illness. This form of symbolic representation lends itself well to various iterations of narrative medicine. However, it is less clear how this kind of representation might inform other manifestations of patient engagement—in particular, those forms of engagement that require high-stakes decision making in curriculum design, assessment, and/or admissions.

The need for clarity. We argue that these three forms of representation— democratic, statistical, and symbolic— coexist within various patient engagement programs. We do not suggest superiority of one form of representation over the other. Indeed, each form has its own conceptual and practical limits. However, we do posit that these different forms of representation imply different practices of recruitment and invite different criteria for determining programmatic success. Generating clarity about what forms of representation are at play—and to what end—will meaningfully inform how patient engagement might be designed, enacted, and evaluated.

Patient Engagement Program Design: Implications for Educators and Patients

Returning now to the practical concerns of educators, the preceding discussion on conceptualizations of representation offers additional insights into the requisite decision making associated with patient engagement programs. Williamson's[15] typology advises a matchmaking process between various forms of patient knowledge and the requirements of the patient engagement activity. Attending to the implicit and explicit forms of representation at play within patient engagement programs sensitizes educators to potential misalignments between declared aims, practices of recruitment, and questions of evaluation.

Take, for example, the two following scenarios. One patient engagement activity could consist of a person who tells his or her illness narrative to a group of trainees. The assumption is that something about this narrative will be meaningful for the trainees and, therefore, relevant to their learning needs. In this scenario, the patient representative is embodying something that is taken

to be reflective of *a* patient experience. Here, the form of representation at play is primarily symbolic. The educator might be concerned with inviting a variety of patients and patient narratives as a way to engage with a range of experiences. The variety is in and of itself an interesting and important part of the learning exercise. Consensus across the various patient participants is not required, nor is such consensus necessarily desirable.

In a contrasting scenario, imagine an engagement activity where a curriculum development committee includes someone from a particular patient group (e.g., parents of a child with autism), with the understanding that the patient representative on the committee will in some way advocate that the priorities of his or her group be reflected in the curriculum. In this scenario, the educator might be concerned with learning from multiple forms of representation: representation that is achieved through participation in patient groups; established ways of collecting information about particular groups; and situated, experiential, and possibly implicit knowledge about a particular patient experience. The educator may implicitly be looking for all three forms of representation: democratic, statistical, and symbolic. Further, it may not be possible—or even desirable—for one patient participant to represent all of these forms of knowledge at once. It becomes important for the educator to consider which form of knowledge is required to inform which stage of decision making. In contrast to current discourses of patient engagement that imply a single, homogeneous patient voice,[21] educators must also be prepared for a multitude of voices—a rich "polyphonia," in Bakhtin's words[22]—not all of whom will agree. If the desired aim of patient engagement is to ensure a fulsome discussion of an important issue, such dissent is a welcome and important part of the process. However, it stands to reason that educators should anticipate disagreement and transparently consider how they will reconcile conflicting advice.

This emphasis on the alignment between forms of knowledge being claimed and the practices of representation that inform those knowledge claims sheds light on a shared concern of program planners and patient participants: how patient participants are to be perceived as

credible, legitimate sources of knowledge. Educators and patient participants both need to be aware of *what* is being asked to be represented: Experiences, hopes, interests, needs, and preferences are all quite different objects of representation. Further, these objects of representation are always in reference to some *subject* of representation—the person or people being represented.[23]

This is where there is the potential for patient engagement programs to get somewhat messy. If the patient participant is under the assumption that he or she is being asked to represent himself or herself, that participant needs to speak to his or her experience. To this end, there are different ways to be considered credible and effective in relaying one's experience. However, if the patient engagement exercise is implicitly designed using democratic principles of representation—for example, engaging a patient representative to participate in decision-making processes to somehow influence decisions to be more generally patient centered—the patient participants may find themselves in an uncomfortable misalignment. How do they present themselves as credible sources of knowledge about patients' experiences more generally?

This advice is distinct from other research efforts that try to improve the fidelity of patient engagement through more and more recruitment techniques. In addition to attending to the matchmaking suggested by Williamson[15] and others, we suggest turning a critical gaze to how different forms of representation are invited, presented, defended, and given legitimacy. This elaborates our understanding of the dilemma of representation. Beyond thinking about how to find "the right patients," we consider how patients are made *to be* "right" for a particular engagement purpose. In doing so, we are able to engage with the critical questions of why engagement might proceed at all.

Concluding Thoughts: An Emphasis on "Why"

Patient engagement in health professions education represents a potentially powerful means to enrich the educational experience while helping to produce health professionals who practice with excellence, compassion, and justice.

At its best, patient engagement might elaborate our collective understanding of important issues, ensuring that a full range of identities, hopes, and concerns may gain a "genuine hearing"[14] in the education of health care professionals. In this sense, engagement of patients in medical education allows for a co-construction—between doctors and other health professionals, patients, and learners—of the professional identity of future health professionals and the capacity that a humanistic orientation to clinical practice requires. To date, educators involved with design and administration of patient engagement programs have been challenged with the problem of representation in a particular way: Do the patients involved in these programs sufficiently represent the diversity of patients one will encounter throughout one's health care career?

In this Perspective, we have introduced different ways of thinking about the dilemma of representation in the context of patient engagement. Viewing representation not just as a democratic or statistical exercise but also as a symbolic one not only allows us to think about "inviting the right people" but also requires us to be more reflexive about how the "right" people are defined. To be the "right" patient for a specific patient engagement activity is not an intrinsic quality of an individual but, rather, is the function of the match between what is being represented, to what purpose, and to which audience. This critical reflection challenges us to question the ways in which individuals' perspectives and life experiences are deemed as credible and legitimate representations and the possible underlying motives for representing patients and their stories in specific ways.

While we have occupied ourselves with questions of who and what is being represented, the ultimate concern is *why* representation is attempted at all. Previously, the question of *why* has most often been dealt with in a technical sense. As we have acknowledged, an engagement exercise intended to teach clinical skills is certainly different from an engagement experience intended to relate the experience of illness or to bring into question various entrenched forms of stigma. Yet, how to do patient engagement well is not entirely a technical question. It is also a deeply ethical one,

one that is wrapped up in who we are as a society and who we collectively want to be. Attending to these notions of representation and being reflexive about our practices—including who has the opportunity to set the agenda for the engagement exercise—are all part of our moral and ethical obligation as educators.

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