

Sharing Health Decisions

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FROM THE EDITOR

The Importance of Sharing Health Decisions

Alexander T. Yahanda, MS

Illness and injury impact patients far beyond the physical or biological changes they inflict. They can strip patients of autonomy, present new or overwhelming information, and make the future even more uncertain. The pathogenesis of a particular medical condition may be the same among patients, yet the context of treatment is distinct since individual patients' preferences and goals differ. Often, disease and medical treatment require patients to take stock of their entire life—what they value, what they want from their care, and what they hope to achieve moving forward. As such, physicians must be able to take all these patient characteristics into account. This partnership demands more than merely a patient coming to a physician for help and the physician providing a service in return. Gone is the era in which physicians alone could make the most important decisions for patients. Today's physicians should not use their expertise to drag a patient towards a particular endpoint; physicians and patients should be partners, traversing a treatment path in tandem, both contributing to crucial discussions.

But how can patients truly receive care that is sensitive to their values and desires if they do not appreciate or feel included in important decision-making moments? Mounting evidence indicates that patients may not comprehend their diagnosis or treatment options,^{1,2,3,4} that physicians define successful outcomes (for instance, the notion of “cure”) differently than patients,^{5,6,7,8} and that patients frequently have unmet communication or shared decision-making needs,^{9,10,11,12} among other barriers. The decision-sharing process, unfortunately, is flawed and unsatisfying for many patients, even if physicians believe that shared decision making is being implemented.¹³

This theme issue of the *AMA Journal of Ethics* on the topic of sharing health decisions addresses these shortcomings. What happens, for example, when patients come to **regret their treatment** decisions, when patients **misinterpret a clinical research trial** as a novel therapeutic opportunity, or when adolescents and parents are at odds over the decision-making process? What does a proper model for sharing health decisions look like? How can we **train physicians** to more effectively incorporate patients into the decision-making process, and how do **time constraints** or **new technologies** affect decision making? Indeed, should every patient even be **considered eligible** for shared decision making? This issue will address these topics and more to synthesize discourse about shared decision making that is applicable to all medical specialties, adult or pediatric, surgical or nonsurgical.

Of course, a single theme issue such as this one cannot provide an all-encompassing overview of shared decision making and the ways in which it could be improved. But the hope is that these articles will serve as a reminder to clinicians to remain conscious of this vital practice during each clinical encounter. Reinforcing the need for decision sharing will help realize the goal of a patient-physician relationship that is open, trusting, and truly patient centered becoming a reality for ever more patients.

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CASE AND COMMENTARY

When a Patient Regrets Having Undergone a Carefully and Jointly Considered Treatment Plan, How Should Her Physician Respond?

Luke V. Selby, MD, MS, Christopher T. Aquina, MD, MPH, and Timothy M. Pawlik, MD, PhD, MPH, MTS

Abstract

Shared decision making is best utilized when a decision is preference sensitive. However, a consequence of choosing between one of several reasonable options is decisional regret: wishing a different decision had been made. In this vignette, a patient chooses mastectomy to avoid radiotherapy. However, postoperatively, she regrets the more disfiguring operation and wishes she had picked the other option: lumpectomy and radiation. Although the physician might view decisional regret as a failure of shared decision making, the physician should reflect on the process by which the decision was made. If the patient's wishes and values were explored and the decision was made in keeping with those values, decisional regret should be viewed as a consequence of decision making, not necessarily as a failure of shared decision making.

Case

Ms S is a 60-year-old woman with stage I breast cancer. After diagnosis, she was referred to a surgical oncologist, Dr J. Over the course of several visits, Dr J and Ms S considered risks and benefits of 2 primary treatment options: breast-conserving surgery with follow-up radiation and total mastectomy, which generally does not require radiation. The patient and surgeon agreed that a left total mastectomy would be best.

The mastectomy went well, and, during a follow-up visit, Dr J reported good news: there was no evidence to suggest that Ms S's cancer had spread beyond her breast. Ms S was pleased to hear this news. She also seemed worried, however. "So, I was reading that there is no difference in survival between breast-conserving surgery and mastectomy."

"Yes, you're right. But as we discussed before your surgery, mastectomy patients are less likely to need radiation.¹ You didn't want radiation," Dr J responded.

Ms S resumed, "Well, that was what I thought at the time.² But now I wish I'd had the breast-conserving therapy with the radiation. Maybe I didn't need the more disfiguring surgery."

Dr J listened. “I think I understand your concerns, yet I think we had a good discussion about the decision we made together. We talked through all the relevant details, and you seemed to understand them thoroughly at the time. That was important to both of us. I think this decision was well made and had a good outcome. That said, I understand that postsurgical hindsight can make us think differently about what the details mean at different times in our reflections. Why don’t we talk more during your next follow-up visit?”

Ms S agreed, wiping a tear from her face. Dr J wondered if she could have done or said more to help Ms S with her feelings of postsurgery regret.

Commentary

This case vignette highlights decisional regret, which is one of the possible consequences of the patient decision-making process when there are multiple treatment options available. Although the process of **shared decision making**, which appears to have been carried out in this case, is utilized to help guide the patient and the physician to come to a mutually acceptable and optimal health care decision, it clearly does not always obviate the risk of a patient’s regretting that decision after treatment. Ironically, the patient might end up experiencing more regret after participating in a decision-making process in which more rather than fewer options are presented and in which the patient perceives the process as collaborative rather than paternalistic. For example, among men with prostate cancer, those with lower levels of decisional involvement had lower levels of decisional regret.^{3,4} We argue that decisional regret does not mean that shared decision making is not best practice, even though it can result in patients being reminded of their role in the decision and associated personal regret with that decision.

Shared Decision Making

Shared decision making has been defined by Elwyn et al as “an approach where clinicians and patients make decisions together using the best available evidence” and patients are supported to consider options and to achieve informed decisions.⁵ As opposed to the paternalistic approach to health care commonly used in the past, shared decision making respects patient autonomy while also adhering to 3 key principles of health care ethics: (1) beneficence, or a physician’s duty to act for the good of the patient; (2) nonmaleficence, or avoidance of harm to the patient; and (3) justice, understood as an equal distribution of scarce resources.⁶ When these 3 key principles are combined with the treating physician’s duty to respect the patient’s autonomy in the decision-making process, the appropriate approach for decisions that are not time sensitive is shared decision making.

Three elements are required for the shared decision-making process to be effective. First, both the physician and patient must recognize that a treatment decision needs to be made. Second, both the physician and patient need to understand the risks and benefits of each of the treatment options. Third, the decision must take into account the physician’s direction and the patient’s preferences and personal values.⁷ Shared decision making is best utilized when a decision is preference sensitive in that there is more than one medically reasonable option available and the best option depends on an individual patient’s preferences and circumstances.^{7,8}

Decisional Regret

Decisional regret is a relatively new area in oncology research and refers to a highly negative emotion that results from uncertainty as to whether a treatment choice was the best among several options or a suboptimal outcome caused one to feel that a different choice might have been more desirable.⁹ Whether decisional regret is a failure of shared decision making¹⁰ or a consequence of decision making is debatable. In order to understand the origin of a patient's feeling of regret, it is important to appreciate that there are different types of regret. Patients might regret their decision based on (1) the outcome of the decision, (2) the treatment option they decided upon, or (3) the process by which they came to their decision. A patient who regrets the foreseeable or unforeseeable outcome of the decision wishes that she had picked a different treatment. For example, the patient might believe, *If only I had picked the mastectomy instead of the lumpectomy and radiation, the cancer would not have come back* (regardless of the published data that led to her initial decision). A patient who regrets the chosen treatment option itself might wish, as did the patient in the current scenario, that she had picked the lumpectomy and radiation instead of the lumpectomy (regardless of any long-term outcome). Finally, a patient might be dissatisfied with how the decision itself was made due to lack of involvement or being rushed or ill-informed, for example.¹¹ One might experience one type of regret but not others, or the overall experience of regret might be a combination of all 3 types.

Both *option regret* (ie, "picking the wrong door") and *process regret* (eg, having made a decision too quickly or without sufficient involvement) can be associated with self-criticism and anxiety and even depression.¹² Patients experiencing these types of decisional regret can be angry at themselves, at the process, and possibly even at the physician for having made a seemingly poor choice, given that they perceive the decision-making process as retrospectively unjustified and the outcome as being worse than what it would have been had the other option been chosen (eg, disfigurement from total mastectomy vs burden of radiation following partial mastectomy). Moreover, for patients who perceive the process to be at least in part unjustified, the intensity of the feeling of regret is dependent on the importance of the outcome.¹⁴ Shared decision making affords the opportunity to reduce both option and process regret, mostly by slowing down the conversation between the patient and the physician to allow the patient to more fully elaborate treatment goals and preferences.

The patient in the case made the decision to undergo a **total mastectomy** instead of breast-conserving surgery and subsequent radiation, which has an equivalent oncological outcome.¹³ That is, she opted for the morbidity of a larger surgery—removal of the entire breast—and skin numbness (mastectomy) instead of a smaller and less morbid surgery (lumpectomy) combined with the inconvenience of radiation therapy (generally 5 days a week for 5 or 6 weeks) and delayed skin changes associated with radiation therapy. Following her recovery from surgery, she now regrets this decision: "Well, that is what I thought at the time. But now I wish I'd had the breast-conserving therapy with the radiation. Maybe I didn't need the more disfiguring surgery."

The patient is experiencing option regret: she made the decision to undergo mastectomy in order to avoid radiation therapy, but she now regrets the extent of surgery necessary to avoid radiation therapy. She does not know what life would have been like had she picked the other treatment option, but, having experienced the results of her decision, she now regrets the decision.¹⁴ In regretting the treatment whose outcome she has experienced ("disfiguring surgery"), she also might be experiencing process regret. She

suggests that perhaps the decision was made without her full understanding of the 2 surgical options and the cosmetic effects of a total mastectomy when she states, “Maybe I didn’t need the more disfiguring surgery.” Given that Ms S is clearly distressed, as she wipes a tear away, she may feel responsible and be blaming herself for a decision she now regrets. In this case, would a more effective shared decision-making process have made a difference?

Just because a decision was made in concert with the patient after providing information appropriate to the patient’s level of understanding does not mean that the patient will end up not regretting the decision. In the current case, the patient regretted the chosen treatment option despite what appeared to be a well-reasoned discussion and decision to undergo mastectomy in order to avoid the burden of radiation therapy. **Decision aids** and supports have been posited to reduce decisional regret.^{14,15}

Failure of Shared Decision Making?

The absence of decisional regret does not necessarily mean that the shared decision-making process was a success.¹⁴ Rather than judging the success of the process in this way, the physician should reflect on the conversation and ensure that the tenets of medical ethics have been upheld. Was the physician acting in the best interest of the patient? Were the risks and benefits of, and alternatives to, the different treatment options explained? Specifically, when there are multiple equally efficacious but clinically different options available, were the differences among all options thoroughly discussed? Was the prospect of decisional regret and what that might mean for future therapy discussed? Were the possibilities of over- or undertreatment discussed with the patient? And, lastly, did the patient make up their own mind? If the physician acted with beneficence, nonmaleficence, justice, and with respect for patient autonomy, then the process can be considered ethical even if the patient later experiences some level of decisional regret.^{9,10}

Decisional regret is often a natural consequence of many decisions. Rather than being a failure of shared decision making, decisional regret can be a consequence of even appropriate shared decision making, such as occurred in this vignette. Key to ensuring shared decision making is agreement between patients and physicians regarding how the decision should be made and upholding the principles of medical ethics during the decision-making process. If the physician had the patient’s best wishes in mind while relaying the necessary information, if the information was relayed in a way that the patient understood, and if the patient’s autonomy was preserved during the process, then decisional regret might not be a failure of shared decision making, as regret cannot always be avoided. That said, the physician’s emphasis on good communication, relationship building, and on assessing the **patient’s desired level of involvement** in the decision-making process should help to minimize the possibility of decisional regret.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY

Sliding-Scale Shared Decision Making for Patients With Reduced Capacity

Tim Lahey, MD, MMSc and Glyn Elwyn, MD, PhD, MSc

Abstract

Shared decision making honors patient autonomy, particularly for preference-sensitive care decisions. Shared decision making can be challenging, however, when patients have impaired decision-making capacity. Here, after presenting an illustrative case example, this paper proposes a capacity-adjusted “sliding scale” approach to shared decision making.

Case

Dr Q is an academic hepatologist meeting a new patient, Mr R, for newly diagnosed cirrhosis. The patient has clear signs of liver dysfunction and has already been admitted to the hospital previously for a gastrointestinal bleed related to esophageal varices. He also has chronic obstructive pulmonary disease, obesity, and poorly controlled type 2 diabetes mellitus.

Dr Q and her student, Ms G, interview and examine Mr R together. They learn that Mr R did not complete high school and lives on what he calls “the wrong side of the tracks.” He lives alone and drinks 4 beers daily. He thinks his brother might have had “liver problems,” too.

As the conversation unfolds, it becomes clear that Mr R does not know why he’s in clinic today. “My doc said it was something about my liver, but...” He shrugs.

Ms G and Dr Q teach Mr R about cirrhosis. They emphasize the importance of alcohol abstinence and start to explain that further workup is necessary—including, potentially, a liver biopsy. Their goal is to enter into shared decision making with Mr R about liver biopsy.

Mr R holds up his hand midway through their explanation and says, “I’m not a detail guy, Doc. I trust you. You tell me what to do, and I’ll do it.”

They talk more, and, ultimately, Dr Q asks, “Do you have any questions for me?” Mr R pauses for a second, starts to ask a question, and then tapers off.¹ Finally, he says, “Whatever you say, Doc. I’m in your hands.”

In the hallway, after Mr R has left to reschedule a follow-up visit, Ms G asks, “Did he really understand what we were talking about?” “Great question!” says Dr Q. “I have no idea. How can we be patient centered if the patient can’t or won’t tell us what he wants?”¹

Commentary

Shared decision making, in contrast to the parentalism of yesteryear, achieves the foundational bioethical value of **respect for patient autonomy**.² Shared decision making is also good medicine: it improves patient understanding of medical options, deepens patient trust, and alleviates decisional conflict.^{3,4,5} These proven benefits of shared decision making accrue even though—or perhaps because—shared decision making is strongly influenced by complex factors such as cultural context, personal experiences, and social relationships, including relationships with clinicians.⁶

Shared decision making also fulfills the ethical duty to allocate resources wisely. First and foremost, shared decision making ensures that we invest health care resources in agreed-upon rather than presumed patient needs. By leading to care decisions by patients that tend to be more conservative than the care physicians assume patients would want, shared decision making likely reduces total health care expenditures,^{7,8} although we predict the magnitude of savings will vary from decision to decision.

Like most patients, physicians generally support shared decision making as long as patient decisions do not preclude the provision of high-quality care.^{9,10,11} However, many patient and clinician factors decrease the likelihood that shared decision making will occur.¹² Prominent among these factors is impaired patient decision-making capacity. This impairment, and how to navigate it, is the focus of this article.

Impaired Decision-Making Capacity

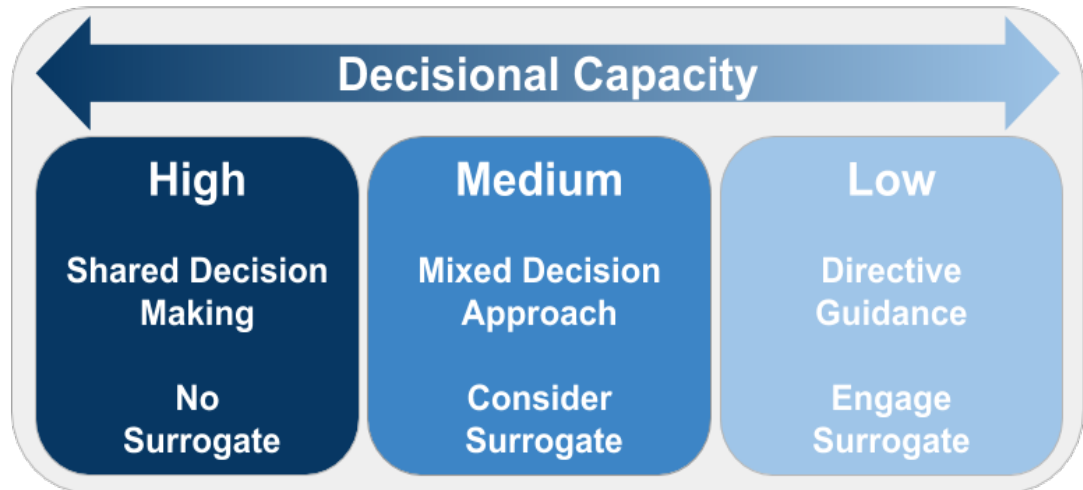
Shared decision making requires that the patient have some degree of decision-making capacity. Decision-making capacity entails patients’ ability to understand their decision, appreciate the consequences of each alternative, and communicate their wishes and rationale.¹³ The high prevalence of reduced decision-making capacity in some settings can thus make shared decision making a challenge. For example, although fewer than 3% of elderly patients in the general population lack decision-making capacity, a 2011 study found that decision-making capacity was impaired in 26% of hospitalized adults, 44% of nursing home residents, and 54% of patients with Alzheimer’s dementia.¹⁴

A common misconception is that patients who have impaired decision-making capacity cannot be expected to engage in shared decision making. Yet decision-making capacity is far from a binary phenomenon: it can be whole, partial, or absent; and **decision-making capacity varies** from decision to decision as well as from time to time.¹⁵ A mildly cognitively impaired patient might be capable of deciding that she wants surgery after failed medical therapy for knee osteoarthritis but be unable to weigh complex decisions regarding the various surgical options available. Alternatively, a fragile elderly patient receiving opioid treatments for pain might be perfectly capable of shared decision making in the morning but be cognitively impaired later in the day after his pain medications have taken effect.

Given situational and temporal variation in patient decision-making capacity and misconceptions of impaired decision-making capacity, clinicians may be tempted to deny patients the opportunity to engage in shared decision making. Nevertheless,

clinicians should assess capacity in a decision-specific manner while tailoring their approach to shared decision-making to patient decision-making capacity. We call this tailored approach *capacity-adjusted sliding-scale shared decision making* (see Figure).

Figure. Capacity-Adjusted Sliding-Scale Shared Decision Making



Tailoring Shared Decision Making

Capacity-adjusted sliding-scale shared decision making combines the assessment of patient decision-making capacity and the tailoring of shared decision making to patient capacity. This intermingling of processes is organic; the elicitation of patient preferences often yields information about patient decision-making capacity, while capacity assessments frequently yield information about patient preferences.

There are 5 steps in the capacity-adjusted sliding-scale shared decision-making approach:

1. Assess the patient's decision-making capacity and openness to shared decision making in 3 stages that we call *team talk*, *option talk*, and *decision talk*.¹⁶
 - a. *Team talk*. Explain that a decision is needed and that you, as a patient's clinician, will support the patient's decision-making process.
 - b. *Option talk*. Explain the options in terms that are clear, accessible, and relevant to the patient's goals.
 - c. *Decision talk*. Elicit patient preferences to the extent possible, which is critical to successful shared decision making.¹⁴
2. Reflect on whether the steps above suggest that patient decision-making capacity is impaired, and, if required, engage formal assessment by psychiatry of a patient's decision-making capacity or formal consulting with ethics.
3. Tailor next steps to patient decision-making capacity. When patient decision-making capacity is impaired, take a more directive approach and engage surrogate decision makers more intensively.
4. Reassess both patient preferences and decision-making capacity over time.

5. Close the conversation with patient and any involved surrogate decision makers by asking how well the process of shared decision making worked for them and whether they have any questions about future conversations.

The Figure depicts 3 levels of shared decision making that depend on degree of impairment, but, of course, there are innumerable degrees of impairment in patient decision-making capacity.

The engagement of **surrogate decision makers** can also be tailored to patient decision-making capacity. We invite clinicians to engage surrogates at all decision points, of course, but as highlighted in the Figure, surrogate decision maker engagement becomes progressively more indispensable as patient decision-making capacity wanes. When patients can make simple decisions (for instance, whether they want surgery for a given malady) but cannot engage nuanced decisions (ie, they cannot choose between competing surgical options), then a surrogate decision maker can provide more nuanced input that builds on the patient's preferences. For patients who lack decision-making capacity entirely, a surrogate decision maker decides on their behalf. There are infinite gradations of patient decision-making capacity and thus infinite ways surrogate decision makers can tailor their support of patients' goals of care.

Although surrogate decision makers are the best option when patients are unable to make decisions independently, they are not perfect. One systematic review found that surrogate decision makers represent patient preferences accurately only 68% of the time.¹⁷ Hopefully, the increasing utilization of living wills and decision support tools will improve surrogate decision maker accuracy.

Beyond supporting optimal accuracy of surrogate decision making, clinicians must take into account surrogates' preferences regarding how they represent patient wishes. Archetypal surrogate roles in decision making have been defined, including preference advocates (who focus on patient values) and clinical facilitators (who focus on clinical information).¹⁸ These archetypes correspond loosely to the needs of patients with more or less decision-making capacity and thus to sliding-scale shared decision making. When there is mild impairment of patient decision-making capacity, surrogate decision makers often act as a preference advocate, whereas surrogates become more of a clinical facilitator as patient decision-making capacity wanes.

Directive clinician (or surrogate) decision support for patients with impaired decision-making capacity is parental.² A common misconception is that **parental decision support** conflicts with the patient-centered nature of shared decision making. In fact, shared decision making can be understood and enacted through many patient-physician models, including parentalism, and is best understood as allowing clinicians flexibility to tailor their approach to patient capacity and preferences.¹⁹ Some patients might feel their preferences have been ignored or sidelined by a clinician taking a parental approach, while others might feel they've had inadequate guidance if a clinician is insufficiently directive. If the clinician takes the approach preferred by the patient and most appropriate to the patient's decision-making capacity, then arguably patient autonomy is more respected than if the clinician were to hew dogmatically to a patient-driven approach contrary to the patient's wishes or capacity.²⁰ The unavoidably subjective determination of patient decision-making capacity and preferred decision-making style is, of course, susceptible to clinician bias,²¹ but fear of this bias should not

dissuade clinicians from attempting to the best of their ability to tailor their shared decision-making approach to patient needs and preferences.

During sliding-scale shared decision making, clinicians might encounter patients who are reluctant to engage in shared decision making.²² Some patients might be unfamiliar with shared decision making, feel they have insufficient expertise to give an opinion, or be unaccustomed to having their preferences elicited by clinicians. With further education and coaching, they might well engage productively. Other patients will articulate a more steadfast preference for a directive clinician style. Much as aligning the approach to shared decision making to patient decision-making capacity honors patient autonomy, so too does tailoring the decision-making process to patient decision-making preferences.

Returning to the case, it is unclear whether Mr R lacks decision-making capacity or if he simply prefers a more directive clinician style. We would devote a conversation to the formal assessment of his decision-making capacity at the same time that we attempt to elicit his decision-making preferences. This approach would ensure that next steps in the liver biopsy decision both align care to Mr R's preferences and respect his autonomy.

Sliding-Scale Benefits

Broadening shared decision making to include patients with impaired decisional capacity would expand the uses—and potentially the benefits—of shared decision making. Coupled with other logistical means of aligning the method of decision making to patient preferences, such as decision aids and patient-reported outcome measures,²³ capacity-adjusted sliding-scale shared decision making is well aligned to the preeminent goal of providing the highest quality care in a fashion that fits patient preferences and ameliorates the high cost of health care delivery today.²⁴

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Glyn Elwyn has edited and published books by Oxford University Press and Radcliffe Medical Press that provide royalties on sales, and he owns copyright in measures of shared decision making and care integration—namely, CollaboRATE, IntegRATE, ConsiderATE, CoopeRATE, ToleRATE, and Observer OPTION(5) and Observer OPTION(12). In addition, he has in the past provided consultancy for organizations, including Emmi Solutions, LLC; National Quality Forum; the Washington State Department of Health; and SciMentum, LLC. He is the founder and director of &THINK, LLC and SHARP NETWORK, LLC, and serves as an advisor or consultant for Access Community Health Network, Chicago; EBSCO Health; Bind; PatientWisdom, Inc; and Abridge AI, Inc. The other authors had no conflicts of interest to disclose.

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CASE AND COMMENTARY

Can Consent to Participate in Clinical Research Involve Shared Decision Making?

Haley Moulton, Benjamin Moulton, JD, MPH, Tim Lahey, MD, MMSc, and Glyn Elwyn, MD, PhD, MSc

Abstract

Shared decision making honors patient autonomy and improves patient comprehension and therefore should be a part of every clinical decision a patient makes. Use of shared decision making in research informed consent conversations is more complicated due to diverse and potentially divergent investigator and patient interests, along with the presence of clinical equipoise. This article clarifies these different interests and discusses ways in which shared decision making can be applied in research. Provided there is transparency about competing interests, patient-centered and values-focused communication approaches embodied in shared decision making can support the ethical recruitment of patients for clinical research.

Case

Dr T is a rheumatologist and principal investigator in several clinical trials on biologic agents. One of her patients, Mr X, has rheumatoid arthritis that has not responded well to standard treatment. Dr T approaches Mr X about enrolling in a phase II trial, the purpose of which is to evaluate the efficacy, safety, and dose specifications of a new monoclonal antibody. Dr T explains the trial's design to Mr X, emphasizing the possibility that he would not receive the antibody if he is randomized to the placebo arm of the study. Dr T also explains that, if he does receive the antibody, Mr X could experience negative side effects and complications. Mr X agrees to participate in the trial.

About 2 weeks into the trial, during a follow-up visit, Dr T asks Mr X about his responses to the experimental agent. Mr X says, "Thank you, Dr T, for letting me try this treatment." Dr T explains that the antibody is neither a treatment nor (even anywhere near being) an approved clinical intervention. Dr T reminds Mr X of the trial's goals. Mr X responds, "I'm so lucky I have a doctor like you who can use research to help patients in ways other doctors can't. This new medicine is great."

Dr T wonders how to respond.

Commentary

Shared decision making is a pivotal way to uphold the foundational bioethical value of respect for patient autonomy.¹ Shared decision making involves eliciting patient preferences, aligning clinical care to those preferences, and ensuring that this process is made clear to the patient. Shared decision making thus improves patients' comprehension of their options, deepens the therapeutic alliance, and helps patients feel more comfortable that health care decisions match their goals of care.^{2,3,4}

Shared decision making can be an appropriate component of subject enrollment in clinical research studies, but the coexistence of a patient-centered approach with complicated investigator motivations—along with **clinical equipoise**—warrants an alternative approach to shared decision making. In this article, we summarize the basic approach to shared decision making and how it should be altered in the context of clinical research.

Practice vs Research

In clinical practice, shared decision making involves bidirectional communication between patient and clinician, in which both parties pursue high-quality care aligned to patient preferences, values, and goals of care.⁵ The clinician might have a personal preference for a particular approach, but this preference should be subordinate to the patient's direct clinical needs.

Clinical research brings different and often more complicated interests to the fore (see Table). These interests can be competing and affect the utility as well as the efficacy of shared decision making for the purpose of recruiting subjects for clinical studies.

Table. Interests of Clinical Practice vs Research Consent

Interests	Setting	
	Clinical Practice	Clinical Research
Public	<ul style="list-style-type: none">• Public health in general• Wise resource allocation• Suppression of transmissible diseases	<ul style="list-style-type: none">• Advancement of science
Institutional	<ul style="list-style-type: none">• Application of standard of care• Protection from legal risk by robust disclosure of risks benefits and alternatives	<ul style="list-style-type: none">• Grant funding• Prestige• Public trust
Clinician	<ul style="list-style-type: none">• Good health outcome for patient• Connection to patient• Good outcome metrics in eyes of institution	<ul style="list-style-type: none">• Patient safety and well-being• Good will between clinicians and investigator colleagues
Investigator	<ul style="list-style-type: none">• Not applicable	<ul style="list-style-type: none">• Grant funding• Prestige• Smooth enrollment of subjects

Patient	<ul style="list-style-type: none"> • Better health • More engagement • Understanding of risks, benefits, and alternatives • Connection to clinician 	<ul style="list-style-type: none"> • Altruism • Access to cutting edge therapies • Potential therapeutic misconception
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In contrast to clinical practice, an investigator enrolling a potential research subject is acting more on self-interest while also furthering the public interest in the advancement of science. She wishes to reach target enrollment smoothly, swiftly, and within budget. She seeks scientific discovery, career advancement, ample funding, and the like. The potential research subject might also have complicated interests at play in the decision to enroll in a research study. For example, the potential research subject may be motivated by altruism or the desire to access cutting edge therapies, and he may be subject to therapeutic misconception—the belief that he is sure to benefit therapeutically from research engagement.⁶ At times, the interests of investigators and potential research subjects can compete, such as when an investigator derives monetary or other less tangible benefits from enrolling subjects in a trial that might engender risks a subject would prefer to avoid.

Equipoise

Diverse and potentially competing interests are not the only reason shared decision making in the research context differs from that of clinical practice. The existence of clinical equipoise—ie, uncertainty about the relative therapeutic benefit of every arm of a trial—alters the role of shared decision making when consenting a potential subject to participate in clinical research. In the clinical setting, expected outcomes of a diagnosis or treatment are reasonably well known and can be aligned to patient goals of care. By contrast, the validity of clinical research requires clinical equipoise. In the presence of equipoise, it is not clear how the decision at hand will or will not further the research subject’s values and goals. This uncertainty must be clear to the patient to avoid therapeutic misconception and thus to orient the patient to valid interests in study participation, such as altruism, curiosity, and trust in the investigator. Without clarifying that uncertainty exists as to the relative superiority of any given treatment, it would be easy for the investigator’s personal interests (such as monetary incentives for subject recruitment or pursuit of career advancement) to swamp the larger subject-centered values that more properly should motivate recruitment and the subject’s personal decision about whether or not to participate.

The key differences between investigators’ and subjects’ interests and the existence of clinical equipoise inform the approach to shared decision making in the research context. We will summarize the basic structure of shared decision making and how its application changes in informed consent conversations with potential clinical research subjects.

Shared Decision Making in Research

In clinical practice, shared decision making generally involves 3 components: (1) assessing health literacy in order to properly clarify the decision at hand, (2) discussing risks and benefits, and (3) explicating how different options align with a patient’s personal context and overall goals.⁷

Assessing health literacy is an essential first step in the shared decision-making process to determine the appropriate language to convey options, risks, and benefits in a manner the patient understands. It is the clinician's responsibility to translate the language of medicine into the vernacular. If 2 parties in a conversation are speaking different languages, the conversation goes nowhere. Once patient and clinician share a common language, only then can the conversation move towards a meaningful discussion of the available options. Perhaps the most pivotal part of shared decision making is what follows—eliciting the patient's preferences and values and explaining how potential decisions and outcomes align with these preferences and values.

In the research context, consent to be a research subject can involve shared decision making, but the process is modified to address the different interests of subjects and investigators as well as the existence of equipoise. The major steps of the process are as follows:

1. Assess the health and research literacy of the potential research subject.
2. Disclose physician interests in the proposed study.
3. Discuss patient motivations for participation.
4. Translate research methodology and technical language into the vernacular.
5. Explain potential risks and benefits of both placebo and intervention.
6. Assist the patient in picturing how the decision to either participate or not participate in the study would fit into his or her lifestyle.
7. Allow the patient to decide whether to enroll as a human subject.

In discussing clinical research, there are multiple health and research literacy issues that need to be made clear before a potential research subject can truly consent. For example, the investigator must assess potential research subjects' understanding of their own medical condition before discussing their comprehension of a proposed experimental intervention for that condition. Research terminology may be opaque to potential research subjects. Do they understand what *randomization* or *phase II trial* mean? Explaining these complicated concepts in lay language is essential.

Following the health and research literacy assessments, the clinical investigator should disclose relevant personal interests to the potential research subject, including whether the investigator is paid to recruit potential subjects for a clinical trial or has stock in the company funding the study.

After addressing health and research literacy, as well as disclosing potential **conflicts of interest**, the next step is an open and honest conversation about the potential research subject's motivations. This is a crucial step in the shared decision-making process for research consent because of the opportunity to clarify important misconceptions and resolve conflicts of interest. Once motivations and interests of both parties have been made clear and misconceptions corrected, if both the potential research subject and the investigator are comfortable moving forward in the consent proceedings, the next step is to explain what a "study" really means.

Only after motivations and study design and concepts have been made transparent should the conversation shift towards describing potential risks (ie, side effects) or benefits (ie, potential therapeutic outcome based on mechanism of action) of all arms of the study—in this case, the placebo and intervention. Physicians partaking in shared decision making with potential research subjects are presented with the challenge of

both accurately conveying what is known so far about the experimental intervention(s) and clarifying that significant uncertainty regarding the efficacy of the intervention(s) inherently still exists.

What's Needed for Informed Consent

Shared decision making in the research context, conducted as above, supports high-quality informed consent conversations and thus leads to true subject comprehension and better alignment of enrollment decisions to subject values.

Revisions to the Common Rule, a federal law that protects human research subjects—including by obtaining informed consent—support the use of shared decision making in informed consent conversations. Effective January 2019, the Common Rule was revised in an effort to promote respect for the autonomy of human subjects. These revisions to the Common Rule include intensified requirements that subjects be armed with “the information that a reasonable person would want to have in order to make an informed decision.”⁸ Researchers are now required to present not only why someone might choose to participate, but also why someone might choose not to take part in a study.⁸ Furthermore, the Common Rule now specifies that informed consent should not “merely provide lists of isolated facts.”⁸ The US Department of Health and Human Services has defined “key information” that should be included at the beginning of any consent documentation^{8,9} and specified that basic information be provided, including the purpose and duration of a study and the procedures involved as well as reasonable and foreseeable risks, discomforts, and benefits. Each of these features of informed consent can easily be built into the shared decision-making process outlined above, particularly steps 5 to 7.

Traditionally, informed consent forms have consisted of dozens of pages of densely typed text that is not linguistically accessible to or understood by the majority of research subjects.^{10,11} A signature at the end of an informed consent form, therefore, often does not guarantee **true informed consent**. Although recent amendments to the Common Rule aim at improving the informed consent process, the changes do not encompass the wording of consent forms or the order of documentation. The inclusion of shared decision making in research informed consent, by contrast, would address this unmet need.

Comprehension

Coming back to the case at hand, assuming that Dr T has not done so already, she should start with the first step in shared decision making for informed consent: the assessment of Mr X's health and research literacy. No matter how carefully and thoroughly Dr T feels she has described Mr X's role in the study, all of this talk is for naught if Mr X doesn't understand the goals of the conversation. Then we suggest that Dr T disclose her personal interests in the clinical trial if she has not already done so, in part so that Mr X could weigh whether this disclosure affects his interest in participation. Once Dr T and Mr X agree on the goals of the conversation and transparency about mutual interests has been ensured, the two should discuss the necessary study details—including the consequences of agreeing or refusing to participate in the study—even if this means covering some of the same ground. Mr X should be able to describe in his own words what he understands his role in this research to be; this teach-back method has been shown to enhance understanding.¹² In the event that Mr X cannot articulate the inherent risks and benefits of participation in the experimental study despite Dr T's

clarifying and reiterating them, then the only appropriate course of action is disenrollment from the study.

Achieving baseline understanding is essential to informed consent. From the information provided, Mr X appears not to understand what randomization entails, what phase of research he is participating in, and what *treatment* means in this context. Each concept should be clarified, as should Mr X's motivations for participation. Now that their informed consent conversation has been tailored to Mr X's health and research literacy, undertaken with transparency about interests, and focused on aligning a decision about enrollment with Mr X's goals and values, both Mr X and Dr T can be confident that Mr X's decision to participate in research comports with the federal standard for outstanding clinical research.

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Conflict of Interest Disclosure

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CASE AND COMMENTARY

How Should Adolescent Health Decision-Making Authority Be Shared?

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Abstract

Shared decision making (SDM) is used in adult and pediatric practice for both its ethical and its practical benefits. However, its use is complicated with adolescents whose emerging and relational autonomy is distinct from that of adults, who make decisions independently, and children, whose parents make decisions for them. This hypothetical case scenario and commentary provide clinicians with a practical and stepwise approach to SDM with adolescents as well as guidance when SDM breaks down.

Case

Jordan was diagnosed with cystic fibrosis (CF) as a result of newborn screening and referred to a pulmonologist, Dr Fernandez. Jordan's parents Peyton and Avery have worked with Dr Fernandez throughout Jordan's life to make decisions that suit their family's goal of Jordan enjoying as typical a childhood as possible and to empower Jordan with age-appropriate information about CF and treatment-related decisions (Step 0.a in Table).

At age 8, Jordan's maintenance regimen consists of routine chest physical therapy (CPT) and medications, with technology dependence in the form of gastrostomy-tube (GT) nutrition overnight. At a regularly scheduled appointment, Peyton and Avery share with Dr Fernandez that Jordan has started to resist respiratory therapies. Dr Fernandez directs questions to Jordan, asking what makes completing the therapies difficult and if Jordan has any ideas about how to make these better. Jordan shares that he experiences nausea during CPT in the morning when his stomach is full from overnight GT feeds. Dr Fernandez states that the overnight feeds could be reduced if Jordan would be willing to take a can of nutritional supplement orally each day (Step 1.a-d in Table). Jordan agrees, and the dietician sends them home with several flavored nutritional supplements from which to choose (Step 0.c in Table).

At age 13, Jordan visits Dr Fernandez during a CF exacerbation. Pulmonary function tests show that increased home therapies have been insufficient, and Dr Fernandez concludes that a hospital admission is warranted. Jordan knows that admission is important, but he also wants to attend a long-anticipated concert that night. Peyton and Avery confirm that Jordan has been developing the ability to listen to his body and gauge

when he is too sick to participate in activities. Together, the family and Dr Fernandez decide that the admission can be postponed until the following day, as long as Jordan’s symptoms do not worsen (Step 1.d in Table).

At age 16, Jordan’s CF has advanced, and Dr Fernandez refers him to the lung transplantation team for evaluation. Jordan undergoes extensive medical and psychosocial screening, and together with Peyton and Avery, receives education about what the transplantation process and life after transplantation might look like. Although transplantation is risky and will require significant hospitalization, Jordan and his parents decide that the potential for life prolongation outweighs the certainty of spending time at home on comfort-focused therapies (Step 1.a-e in Table).

However, there is disagreement about whether Jordan should be intubated or receive cardiopulmonary resuscitation (CPR) if his condition worsens during the wait for transplantation. The transplant team worries that if Jordan is sick enough to require intubation or chest compressions, it would be unlikely (but not impossible) for Jordan to get well enough to tolerate the transplantation procedure. Jordan has been intubated before and “hated it.” Avery and Dr Fernandez want to ensure that they do “everything possible” to give Jordan a chance at the longest life possible. Peyton is uncertain how to reconcile Jordan’s and Avery and Dr Fernandez’s perspectives. The palliative care team, which was consulted when Jordan was 14 years old, spends time separately and together with Jordan, Peyton, and Avery to allow them to process their feelings about these decisions and weigh the benefits and burdens (Steps 1.e and 2.d in Table). Eventually, Jordan decides that giving his mother the peace of mind of doing “everything possible” is worthwhile, despite his own reservations. Avery clarifies her desire is for intervention if Jordan has an unexpected event that might respond to treatment and states that she will honor Jordan’s wishes to refrain from invasive therapies if there is a slower decline that would be less likely to respond to treatment (Step 1.f in Table).

Table. Strategy for Shared Decision Making With Adolescent Patients and Their Parents

Point in SDM	Strategy
Before a discrete treatment decision needs to be made	Step 0
	a. Get to know the patient.
	a. Set expectations for SDM.
	b. Engage the patient in smaller choices.
	c. Consider consulting palliative care.
When it is time to make a decision	Step 1
	a. Define the medically reasonable options.
	b. Discuss the decision with the adolescent and his or her parent(s).
	c. Make a recommendation, if appropriate.
	d. Honor medically reasonable decisions.

	e. Acknowledge emotions; allow more time for decision making, if possible.
	f. Accept different levels of SDM with different families.
When SDM becomes difficult	Step 2
	a. Consider obtaining an ethics consultation.
	b. If the patient and parent(s) decline all medically reasonable options, consider seeking state intervention to compel the adolescent to undergo the recommended therapy.
	c. If the patient and parent(s) request potentially nonbeneficial or harmful treatments, maintain a therapeutic relationship and be flexible, but consider contacting state authorities to protect the patient from harm if the family elects to pursue a harmful therapy.
	d. If the patient and parent(s) disagree about the best treatment plan and both preferred courses of action are medically reasonable, reengage in SDM but acknowledge that parents have the legal authority to make a final decision.

Abbreviation: SDM, shared decision making.

Pediatric Shared Decision Making

Shared decision making (SDM) is an important aspect of patient-centered medical care because it integrates a patient's (and family's) values, goals, and preferences with a clinical team's knowledge of treatment options and outcomes.¹ Conceptually, SDM holds 2 important bioethical principles in tension—beneficence and respect for autonomy.² Clinicians seek to help their patients by recommending therapies that are medically beneficial. Although adult patients agree to treatments that they believe will suit their values, goals, and preferences, they are also allowed, in most cases, to decline.³

Other principles come into play when parents participate in SDM with clinicians on behalf of children who are patients. Children should be involved in decisions regarding their health, **providing assent** to the degree they are able,⁴ but ultimately it is their parents who have decisional authority.⁵ In these decisions, while beneficence and autonomy continue to be important, protecting children from harm becomes the priority. Indeed, if a family's decision about which treatment to receive or decline puts a child at risk of serious harm, there is both legal and ethical support to override parental autonomy.⁵

SDM with adolescents, who find themselves developmentally and chronologically between childhood and adulthood, is especially hard.⁶ How should clinicians uphold their fiduciary duty to protect patients from harm while respecting parents' legal authority and adolescents' autonomy? *Adolescent autonomy* contains several layers, each of which manifests differently in different individuals.⁷

Adolescent Autonomy

Emerging autonomy. The cognitive and emotional regulation skills required to make decisions evolve during adolescence. It has long been known from laboratory experiments that youth as young as 14 can understand medical information and come

to reasoned decisions resembling those of young adults.⁸ However, teenagers are less likely than adults to engage their rational **decision-making abilities** in emotionally fraught situations with psychosocial implications, such as important or stressful medical decisions.⁹ Clinicians, who have a duty to protect adolescents from harm, must consider if adolescent patients are protecting their own interests when they are engaged in SDM.

Relational autonomy. While some may not consider a decision autonomous unless reached completely independently, it is unrealistic and developmentally inappropriate to expect adolescents (and, most likely, patients of all ages) to be completely independent or to ignore the important people in their lives when making medical decisions.¹⁰ Rather, adolescents commonly consider the perspectives of peers and family as well as how their decisions will impact others. The extent to which adolescents depend on guidance from their parent(s), peers, and other important people in making decisions varies. Life experience and social location contribute to adolescents' desire for independence and belief that their own opinion should be the deciding factor.^{7,11} How hands-off a parent is willing to be depends on his or her parenting style, knowledge and comfort with medical decisions, and culture.^{4,12,13,14} Adolescents might also consider the perceptions and expectations of their peers and social networks when making life choices, including medical decisions.⁹ Finally, medical decisions have reciprocal implications for patients' identity and relationships to others. Adolescents might consider what decision a "good" child, "brave" patient, or "independent" actor would make, thereby infusing their perception of others' opinions into their medical decision. When engaging in SDM, clinicians should seek to understand the extent to which an adolescent is weighing others' opinions in making a decision and if this level of consideration promotes the adolescent's health and healthy relationships.

Strategy for SDM With Adolescent Patients and Their Parents

Ideally, there would be a standardized assessment to determine adolescents' capacity for assent or consent and therefore how involved in decision making they should be. Authors have suggested various tests and considerations.^{12,13,15} However, given the many fluctuating variables involved in adolescent autonomy (eg, **cognitive development**, emotional state, others' influence, and desire for independence), we consider it unlikely that further research will produce an evidence-based, clinically feasible evaluation to neatly solve this complex problem. Therefore, we share our own approach to SDM with adolescent patients and their parents that is outlined in the Table and illustrated in the above case.

1. *Step 0: Before a discrete treatment decision needs to be made*
 - a. Take the opportunity to get to know the patient; the patient's values, goals, and preferences; and how the family makes decisions together.
 - b. Explain that, when it comes time to make treatment decisions, you will seek to respect the opinions of both the adolescent and the parent(s) and ensure that the adolescent remains safe.
 - c. Engage the child or adolescent in small choices related to the patient's care to help the patient practice weighing benefits and burdens in light of his or her goals, values, and preferences.¹⁶
 - d. If the patient has a chronic or potentially life-limiting diagnosis, consider consulting a palliative care team to help the patient and family elucidate their values, goals, and preferences and apply them to future decisions. (Palliative care is not limited to end-of-life care and is not a sign of "giving up.")

2. *Step 1: When it is time to make a decision*
 - a. Use evidence-based medicine and your medical judgment to determine which treatment(s) will benefit the patient or at least enable the patient to avoid serious harm; these are the medically reasonable options.
 - b. Engage the adolescent and the adolescent's parent(s) in a discussion about the medically reasonable treatment options and how their values, goals, and preferences would fit with each option.
 - c. If there is one option that appears medically superior or that you believe best fits the values, goals, and preferences of the adolescent and parent(s), make this recommendation and explain why.
 - d. Allow the adolescent and parent(s) to choose any of the medically reasonable alternatives they believe fits best. Be flexible if there are preferences that can be accommodated without affecting the efficacy of the treatment(s).
 - e. Enhance the adolescent's decision-making capacity by acknowledging and exploring the emotions that the decision brings up. If it seems the adolescent is making decisions based on emotion rather than reason (as is common based on adolescent neurocognitive development in difficult situations⁹), help the adolescent (and family) reflect on their thoughts and explore the values guiding their choice. If possible, give the adolescent and family additional time to consider the options; decision making can pivot from emotional to rational when patients and families have time to process their emotions and deliberate on the impending decision.¹⁷
 - f. Recognize that different families will share similar decisions in different ways based on their ideal of **relational autonomy**. This varied "sharedness" is acceptable as long as the adolescent and parent(s) are comfortable with the process and choose a medically reasonable treatment option.

3. *Step 2. When SDM becomes difficult*
 - a. Consider obtaining an ethics consultant to act as an objective third party in assisting you in weighing harms and benefits and ensuring that everyone's perspective is heard.
 - b. If, after multiple conversations, the patient and parent(s) decline all medically reasonable options, consider seeking state intervention to compel the adolescent to undergo the recommended therapy. Weigh the likelihood and significance of the potential benefit against the risks of breaking the family's trust in the clinicians, the psychosocial harm of forcing an adolescent to act against values in which he or she is highly invested, and the feasibility of forcing someone to undergo therapy.^{7,9} Respectfully explain to the family your concerns and the process of involving authorities.
 - c. If the patient and parent(s) request potentially nonbeneficial or harmful treatments, maintain a therapeutic relationship. Ask questions to gain understanding of the goal behind the family's request and consider if there is a medically reasonable way to meet it. Explain your concerns. Ask what the patient and family think about these concerns. For potentially nonbeneficial treatments, consider multiple definitions of *benefit*. For example, if a treatment aids in prolonging life but cannot provide a cure and the family has expressed that goal, then it may provide benefit of a different sort. Offer a time-limited trial, based on when clinically significant benefit would be expected if the therapy were effective. For potentially harmful treatments, offer to connect the family with other reputable clinicians to get a second

opinion. If these efforts fail and the family plans to pursue harmful therapy—either independently or under the direction of an unqualified clinician—weigh the risk and magnitude of the harm of the planned therapy against that of reporting the family to state authorities. If the harm from the therapy is very likely and serious, inform the family of your duty to contact state authorities to protect the patient from harm.

- d. If the patient and parent(s) disagree about the best treatment plan and both preferred courses of action are medically reasonable, reengage in conversations to elucidate the values, goals, and preferences that drive this difference. Help the family differentiate between essentials and “nice to have’s,” and think creatively about how to meet each person’s essentials. Acknowledge that parents have the legal authority to make a final decision. Ask them to consider the loss of trust and psychosocial harm of forcing an adolescent to act against values in which he or she is highly invested and the feasibility of forcing their child to undergo therapy. Make every attempt to convince the adolescent to agree with the treatment.¹⁸

Conclusion

Adolescence is characterized by emerging and relational autonomy, identity development, and social relationships. All of these factors impact adolescent, family, and clinician medical decision making. Thus, SDM with an adolescent requires a somewhat different strategy than SDM with an adult or a young child’s parent(s). We suggest that clinicians engage with an adolescent patient and his or her parent(s) before a decision is required to understand the family’s treatment values, goals, preferences, and decision-making style and to communicate how decisions will be made together. At the time of a health care decision, clinicians should identify all medically reasonable alternatives and help the adolescent patient and parent(s) to choose among these. Finally, when a shared decision cannot be reached, clinicians must honestly compare the harms and benefits of the proposed action plans and acknowledge parents’ legal authority to decide, as long as the chosen option is medically reasonable. If the family elects to pursue an option that is not medically reasonable, the clinician must weigh the risks and benefits of involving state officials to protect the adolescent from harm. When an adolescent’s emerging autonomy must be curtailed out of concern for the patient’s well-being, it is especially important to treat the adolescent with respect.

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CASE AND COMMENTARY

How Should the Recovery Process Be Shared Between Patients and Clinicians?

Patrick S. Phelan, Mary C. Politi, PhD, and Christopher J. Dy, MD, MPH

Abstract

Illness and injury often entail lasting health and social consequences beyond the acute event. During the immediate and long-term recovery period, consequences of illness or injury can often be mitigated and addressed. As patients and their clinicians discuss care decisions, whether for initial or ongoing management of illness or injury, they must consider patients' personal goals of recovery alongside possible clinical outcomes to choose the best path forward. Understanding the recovery process and patients' and clinicians' decision making requires clarifying the concept of recovery and its significance. This article will describe how shared decision making can support the recovery process using a case example of brachial plexus injury.

Case

Ms M is a 32-year-old, right-hand-dominant engineer who developed weakness, numbness, and shooting pain through her right shoulder and arm 3 months ago, following a fall from a bicycle during a recent vacation. She cannot raise her arm overhead and cannot flex her elbow. Her symptoms are consistent with an injury to the brachial plexus (the network of nerves that connect the spinal cord to the muscles and skin of the shoulder, arm, and hand), which can manifest as weakness or absence of muscle function, loss of sensation, or shooting pain. Nerve regeneration is a lengthy process and many patients experience emotional distress, financial strain, and increased reliance on others during the prolonged recovery.^{1,2,3}

Due to concern for a brachial plexus injury (BPI), Ms M's primary care physician referred her to a peripheral nerve surgeon, Dr D, whom she has been seeing in follow-up for her diagnosis of BPI (attributed to a stretch injury to the nerves sustained in the fall). As is standard of care, Ms M did not receive immediate posttraumatic intervention but has had close monitoring of her motor function, which has unfortunately demonstrated only modest return of function. Dr D counseled her that many patients with her injury (an upper trunk BPI) recover nearly full strength with observation,⁴ and those who do so typically start to see signs of muscle reinnervation by 3 to 6 months.⁵ However, some patients do not have recovery of muscle innervation and may benefit from reconstructive surgery (eg, nerve transfer). At this point in her recovery (3 months from

her injury), early intervention with surgery is a viable option, although it remains unknown whether Ms M would spontaneously regain further function over the coming months. Dr D and Ms M begin a discussion about the choice for early surgery vs continued monitoring, given the considerations involved.

Commentary

As patients and their clinicians discuss care decisions, whether for initial or ongoing management of illness or injury, they must consider patients' personal goals of recovery alongside possible clinical outcomes to choose the best path forward. We consider *recovery* to capture the notion of healing at its most basic level. From a theoretical perspective, Atterbury has suggested that recovery-oriented care entails holistic preservation of the self: "Embedded in a recovery orientation is the understanding that service users [patients] are experts in their own experience, that a diagnosis cannot capture the totality of a person's being, and that effective and ethical interventions recognize the full personhood and rights of service-users [patients]."⁶ Similarly, empirical research on recovery from illness or injury has produced valuable insight into patients' perceptions of recovery. Patients' goals of recovery include common themes of restored function, comfort, and a global sense of normalcy.^{7,8,9,10} The individual nature of **patient recovery goals** and priorities sometimes differ from those of clinicians.⁷

Clinical outcomes during recovery suggest that recovery is an ongoing process, wherein goals (such as functional status) may be attained temporarily and change dynamically over the course of the recovery period.¹¹ Patient and clinician perspectives on and discussions about the recovery process and its implications for patient care should be informed by a shared decision-making (SDM) approach. Understanding the recovery process and patients' and clinicians' decision making requires clarifying the concept of recovery and its significance.

Recovery Planning

SDM is a collaborative process through which patients and clinicians contribute unique perspectives to discussion of care options and aim to achieve consensus by considering medical evidence alongside patient preferences.^{12,13} When there are reasonable alternative courses of care and time to deliberate on them, SDM can be seen as the ideal of patient-centered medicine.¹⁴ Engaging in SDM during illness recovery requires navigating the unique considerations present throughout the recovery process. Prognoses can evolve, and patients' desired outcomes and the feasibility of achieving those outcomes might shift over time, requiring a reevaluation of recovery goals.

BPI provides an excellent example of how SDM can facilitate recovery planning. The physiologic and functional consequences of BPI are significant and measurable (and so can be recognized and tracked by both patients and clinicians),^{15,16} the optimal course of management is uncertain, and the alternative options (waiting vs surgery) are substantially different. Surgery may offer better long-term function and predictable results, but it is invasive, carries some risks, and entails postoperative immobilization, physical therapy, and a total rehabilitative course lasting up to a year or more.⁵ Continued observation carries the risk of additional muscle atrophy, less reliable results, and prolonged loss of productivity. Early surgical intervention is of uncertain value compared to continued waiting and later surgery,¹⁷ and the timing of surgery also involves social-logistical considerations, such as availability of time off from work, coverage of other responsibilities, and **personal assistance** in the postoperative period.

We can explore the use of SDM in this case by considering the perspectives that Ms M and Dr D might bring to the clinical decision (see Table 1).

Table 1. Patient and Clinician Perspectives on Recovery Plan Options

Perspective	Options	
	Continued Observation	Early Surgical Reconstruction
Ms M (patient)	<ul style="list-style-type: none"> • Possibility of spontaneous (near) total recovery in next several months (but involves waiting and uncertainty of recovery) • Option for later surgical reconstruction (but risks regret for wasted time or lost recovery benefit). 	<ul style="list-style-type: none"> • If successful, recovery is faster than later surgery. • If unsuccessful, risks regret, especially if there are complications. Could potentially mitigate regret by having taken action. • Requires general anesthesia; involves arduous postoperative course and transition to physical therapy and social-logistical challenges in immediate postoperative period.
Dr D (surgeon)	<ul style="list-style-type: none"> • Ideal management plan if potential for spontaneous recovery remains (which cannot be known). • Possibility of avoiding surgery entirely, which simplifies rehabilitative course if successful. • If unsuccessful, risks loss of long-term functional potential and worsened rehabilitative course due to excess denervation muscle atrophy. 	<ul style="list-style-type: none"> • Ideal management plan if no remaining potential for spontaneous recovery (which cannot be known). • If successful, minimizes denervation muscle atrophy relative to later surgery. • Surgery and postoperative plan are time sensitive.

In what follows, we use a framework of SDM that includes *team talk* (defining recovery, considering patients' preferences), *option talk* (identifying feasible outcomes, discussing their pros and cons), and *decision talk* (discussing patient preferences regarding the pros and cons of options, planning next steps) (see Table 2).

Table 2. Domains and Goals of Shared Decision Making About Recovery

Domain ^a	Goals	Clinician Communication
Defining Recovery (Team Talk)	<ul style="list-style-type: none">• Elicit goals with open-ended questions.• Operationalize goals (in terms of form, function, or symptom amelioration).	<ul style="list-style-type: none">• What would recovery from this illness/injury mean to you?• What is most important (necessary) for you to have a successful recovery?• What symptoms are most important for you to avoid? What would get in the way of your feeling you had a successful recovery?
Options, Outcomes, and Odds (Option Talk)	<ul style="list-style-type: none">• Identify courses of action.• Identify feasible outcomes.• Estimate probable outcomes, using standards for clear risk communication (eg, absolute risk expressed as X in 100 or X in 1000, keeping denominator constant).	<ul style="list-style-type: none">• Let's review your options (eg, standard, experimental) and talk about why some other options might not work in your case.• Let's review the best possible outcomes for you.• Let's talk about possible harms or downsides of those outcomes.• Let's talk about how likely each outcome might be.
Recovery Planning (Decision Talk)	<ul style="list-style-type: none">• Identify patient preferences.• Reconcile conflicting patient preferences and evidence to ensure understanding.	<ul style="list-style-type: none">• What questions do you have about your treatment options or your recovery goals?• Do you have an idea of which option you would most prefer? OR• Based on what we've discussed about your values and recovery goals, it sounds to me like you might prefer option X.• Based on your priorities, I'm worried that you might be less comfortable with option X than option Y. What do you think?• I agree that option X offers you the greatest potential for recovery. I want to make sure you understand its risks compared to those of option Y.

^a Based on Elwyn et al.¹³

Perspectives on the SDM process. Clinicians' perspectives on recovery may be informed by their professional context. As products of training curricula based in science, physicians such as Dr D might implicitly prefer the apparent objectivity of quantifiable and clinical measures for tracking recovery (eg, electromyography or nerve conduction studies) over qualitative or patient-reported **quality-of-life assessments**. Such

preferences may even be explicit when the available research studies use the same measures to evaluate clinical success.

The experience of life after illness and injury can be contextualized (by both patients and clinicians) in terms of deviations from a patient's baseline status prior to illness or injury—deviations that may span activities of daily living, recreational and occupational activities, and elements of quality of life, such as mood and pain or other discomfort. In the case of BPI, comparative prognostic information can be constrained by the limited and variable nature of outcomes reporting (predominantly pure motor function) in studies of reconstructive surgery.¹⁸ Thus, in discussing surgery decisions with Ms M, Dr D is limited to his own clinical experience (and that of colleagues), the direct evidence provided by outcomes data in the literature, and the extent to which these data pertain to patient-relevant functional improvements.¹⁹

Although clinicians might understand and consider patients' subjective experiences of illness and injury, patients often place a higher priority than clinicians on these experiences. For patients, the social and emotional contexts of health consequences are especially salient and intersect with integral concepts such as independence, confidence, and social or family roles.^{7,9} These differences in perspective offer insight into the approaches that patients and clinicians take in evaluating alternative paths to recovery. In the present case, the choice characteristics most meaningful to Ms M could differ from those most meaningful to Dr D (see Table 1).

Contributions to the SDM process. In general, clinicians' contributions to SDM include clinical expertise (eg, epidemiological, pathophysiological, and other knowledge), the ability to communicate such information effectively, and shared deliberation with patients. For procedural interventions, surgeons like Dr D also bring relevant insight based on their own experience and technical skill, which should inform their assessment of options and might also inform patient expectations. In addition to experiential knowledge of symptoms and functional impairment, patients contribute the value—the importance and priority—they place upon aspects of life relevant to the care decision. Exploring and clarifying these values is an essential element of SDM, as it informs the determination of patients' priorities and preferences for care options and their potential outcomes. In the case example, SDM requires identifying the ways in which Ms M's injury has meaningfully impacted her daily life and clarifying her values with respect to these impacts. For example, Ms M might currently be able to continue working despite her dominant arm weakness, but she may have difficulty with socially meaningful tasks such as driving or caring for children. Each impact can have a different personal significance for her (see Table 1).

Responsibilities in the SDM process. In order to appropriately support deliberation among options, clinicians must aid patients in identifying and prioritizing their goals for recovery. In Ms M's case, it might be helpful to explicitly ask her to consider what would constitute recovery for her.⁸ Clinicians should facilitate deliberation through concrete examples. For example, Dr D might address the goal of functional capability by asking Ms M to identify the impaired tasks she finds most important to master through rehabilitation. He might ask what typical pain severity level Ms M would find tolerable and what behavioral modifications or medications she would be comfortable trying in order to achieve improvement. Clinicians are also responsible for being familiar with estimates of outcomes (when available), evaluating the applicability of these population-based estimates to the patient, and communicating them effectively at each patient's

level of comfort with numbers. This responsibility derives from the clinician's duty to their patient's best interest: the most complete and accurate information for each patient should be identified, just as it should be conveyed to each patient as clearly and accurately as possible.

Although Ms M works as an engineer and likely has high numeracy (ability to understand numeric information), Dr D should take care to use best practices in quantitative risk communication: presentation of **absolute risks** and risk differences (rather than relative measures), use of whole numbers to describe probabilities (natural frequencies), and use of consistent scales for event rates (same-denominator comparisons).^{20,21} To aid communication of this technical information, clinicians can leverage appropriate communication tools such as visual aids, especially when such formal decision aids exist for the clinical choice in question. At the same time, clinicians must acknowledge the uncertainty inherent in **prognostication** and attempt to help patients find comfort with the unknown. Clinicians should have a basic understanding of processes that can impact patient reasoning, such as anticipatory regret (the level of guilt or negative feeling one might experience about a potential outcome, regardless of its likelihood of occurring) and affective forecasting errors (errors in predicting how one might feel in the future).²² Clinicians should use this knowledge to promote productive patient deliberation by probing patients' reasoning ("Tell me more about why you are leaning toward this option") and providing additional perspectives for reflection. Additionally, successful SDM requires patients to engage thoughtfully in the process by identifying and communicating their values and goals and asking any questions they have about the information the clinician provides.

Conclusion

Successful SDM occurs when patients and clinicians fulfill their responsibilities to create a shared concept of recovery that both optimizes clinical outcomes and is informed by patient preferences and goals. Throughout the recovery process, progress or setbacks that inform the patient's prospects may necessitate reevaluation of realistic recovery goals. Although ideal outcomes cannot be expected in every case, involving patients in SDM can make the most of their recovery experience and provide them the best chance at choosing a recovery path that meets both their clinical and their personal needs.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

MEDICAL EDUCATION

How Should Shared Decision Making Be Taught?

Dong-Kha Tran, MD and Peter Angelos, MD, PhD

Abstract

As the field of medicine shifts from a paternalistic to a more patient-centered orientation, the dynamics of shared decision making become increasingly complicated. International globalization and national socioeconomic differences have added unintended difficulties to culturally sensitive communication between physician and patient, which can contribute to the growing erosion of clinician empathy. This article offers a strategy for teaching students how to enter into conversations about shared decision making by bolstering their empathy as a result of exposing them to the many variables outside of their patients' control. Patients' historical and cultural context, gender identity, sexual orientation, and common assumptions about clinicians as well as institutional biases can severely limit students' ability to integrate patients' value-laden preferences into shared decision making about health care.

Introduction

Once viewed as a paternalistic-oriented profession characterized by physicians' overprotection of care recipients, medicine has now shifted towards more person-centered care.¹ In conjunction with international globalization and national socioeconomic disparities, this shift has complexified medical training. Memorable words from the authors' first day of medical school— that “medicine is a service profession”—continue to echo. Our service to patients is to bring extensive medical training and knowledge to bear on their personal, real-life experiences to generate a foundation for shared decision making.

We believe that **teaching empathy** is the best way to prepare students to serve patients. It is not to be assumed that those who enter the profession are inherently empathetic or compassionate. Empathy has been defined, but oversimplified, as “an ability to understand the patient's inner experiences and perspective and a capability to communicate this understanding.”² However, as the current sociopolitical climate has helped make increasingly clear, the disparities and bias suffered by many patients are such that students, let alone health care professionals, might have incredible difficulty in finding common ground with their patients. Institutional and systemic barriers and biases can have drastic but nearly invisible effects on the patient-clinician relationship.

Although empathy serves as bridge between clinicians' and patients' experience, especially if clinicians have had personal experiences with a particular disease process, we argue that the combination of patients' life experiences and illness experience is unique. This degree of complexity encourages a patient-centered rather than a paternalistic approach.

Teaching empathy is no small undertaking, given the insufficient evidence of the effectiveness of educational interventions designed to enhance empathy.^{3,4} We believe that, prior to implementing any such intervention, clinicians must first build a pedagogical foundation. As we shall describe, laying this foundation requires exposing students to diverse patient backgrounds rooted in a complex variety of factors—including, but not limited to, race, gender, culture, lifestyle, and socioeconomic status—through coursework, patient panels, and patient encounters during rotations, residency, and beyond. This cumulative experience leads to broadening of students' perspectives, which foundation is required to support not only empathy but also shared decision making. The goal of this training is for the student to become patients' and other stakeholders' teacher, translator, and guide in the complex medical field where stakeholder preferences are folded into health care decision making, informed consent, and care planning.

Patient Background

Race. There is evidence that minorities' preferences for treatment and disclosure may differ from those of whites. Dula and Williams argue that common assumptions about end-of-life care contradict those of African-Americans, who tend to prefer more aggressive care.⁵ Lack of understanding of apparently irrational demands for treatment can lead to clinician frustration and inability to incorporate patients' preferences in decision making. Contrasting cultures' preferences for diagnosis disclosure are illustrated in "What You Don't Know" (now the film *The Farewell*).⁶ This story, about a Chinese-American family that decides not to inform the terminally ill grandmother of her prognosis, brought into the mainstream the author's struggle straddling 2 cultures and raised many ethical questions about how Western medical assumptions about patient preferences might not be in line with those of other cultures.

Gender and sexual identity. Over the years, there have been large societal shifts in sexual orientation and gender identity. Studies have shown compelling evidence of increased negative health indicators and higher rates of victimization in lesbian, gay, bisexual, transgender, and queer youth.⁷ Although it is clear that health care practitioners must be **comfortable discussing sexuality** and sexual orientation, in one survey of lesbian, gay, and bisexual young adults, 78% of respondents reported that these issues were never discussed at all with their clinician during adolescence and 67% that they would have liked to have had such conversations.⁷

Socioeconomic status. Although there has been a focus on race, gender, sexual orientation, and culture in social psychological analysis of identity, socioeconomic factors such as income and education have also been shown to affect personal and social identities.⁸ Patients of lower socioeconomic status might believe they get lower-quality care based on clinician assumptions about the treatment or medications that patients with fewer resources deserve. Higher education has been shown to increase patient self-advocacy, enabling clinicians greater understanding of presenting concerns and symptoms that may lead to more accurate and timely diagnoses.⁹

As these examples hopefully demonstrate, it is imperative that students be aware of patients' cultural background. Awareness is a valuable tool for health care professionals to open a dialogue and have care conversations with patients that draw on patients' real, individual experiences.

Structural and Individual Bias

In 2003, the Institute of Medicine (IOM) released an extensive report, *Unequal Treatment: Confronting Ethnic and Racial Disparities in Health Care*,⁹ which found that, regardless of socioeconomic and sociodemographic status, racial and ethnic disparities in health care persist and are associated with worse outcomes. The broader historical and contemporary inequalities experienced by minorities in the United States contribute to complex structural and individual biases in many clinical encounters. Since the landmark IOM report, perceptions of health care discrimination have decreased among Latino, Asian, and immigrant individuals but remained consistently high among black individuals.¹⁰ Nevertheless, all of these minorities¹⁰—and among the chronically ill, blacks¹¹—continue to perceive that they are subject to health care discrimination at higher rates than whites.

Multiple barriers can prevent patients from receiving high-quality medical care. Language barriers, for example, contribute to inadequate patient understanding and informed consent, exacerbating health systems problems such as lack of resources, knowledge, and institutional priority. Outside the health system, medications are vastly undersupplied in predominantly minority neighborhoods compared to predominantly white neighborhoods.⁵ Moreover, considerable research in the field of psychology has shown that the most well-meaning clinicians are socialized to have implicit and explicit **stereotypes**.^{5,12} Clinicians making judgments under the pressure of time and resources are susceptible to information shortcuts (ie, stereotypes) due to lack of information.

Structural biases are present in legal, regulatory, and policy-making areas. The IOM noted that racial and ethnic minorities are more likely than whites to be enrolled in “lower-end” health plans with stricter limits on covered services, with the result that health care financing and delivery are fragmented by socioeconomic status.^{3,5} Conversely, at the opposite extreme is the highly publicized case of Steve Jobs reported in 2009 by the *Wall Street Journal*. California-resident Jobs had the means to receive a liver transplant in Tennessee with a median waiting list time of 48 days (compared to the national average of 306 days).¹³

All of the above factors may contribute to patient mistrust and treatment refusal, from which physicians can wrongly infer that patients are unsophisticated and uneducated.⁵ However, in the context of systemic prejudices, students may begin to understand how patient decisions may be completely logical.

Compassion Fatigue

Compassion fatigue, a component of burnout, was first studied in crisis counselors and mental health practitioners¹⁴ and is now commonly studied in palliative care nursing clinicians.¹⁵ It is a result of repeated exposure to stressors, including death and dying, vicarious trauma, expanding workloads, and a feeling of impotence to do more to help in the face of limited resources.^{4,14,16} Although we cannot speak with authority on the matter, communication barriers—such as misunderstanding of patient assumptions and perceptions—arguably contribute to clinician frustration and compassion fatigue. This misunderstanding can lead to patient nonadherence that can then lead to ineffective

treatments—all of which are possibilities that are exacerbated by the time constraints of clinical practice. Tempering and modulating what we assume about our patients can facilitate starting a health care conversation.

Strategies for Education

In light of factors that contribute to disparities in health care, teaching students how to facilitate shared decision making will require more than knowledge of disease pathophysiology and its treatment that medical education currently requires. Despite limited evidence of the effectiveness of empathy-enhancing interventions, we believe empathy should be taught through longitudinal exploration and discussion of the many variables that affect patients' psychosocial identities and contribute to health care disparities. Broadening students' cultural perspectives through teaching empathy would facilitate their understanding of patients' preferences and prior health care decisions and thus facilitate shared decision making.

It would be easy to infer from the discussion thus far that we believe that paternalism is bad and respect for autonomy is good, but the role of the 2 orientations in shared decision making is much more complicated. Ideally, paternalistic attitudes stem from protectiveness and thus imply benevolence, but they risk overprotectiveness—resulting in loss of patient autonomy and possibly negative impacts on patients' mental health.¹ Respecting patient autonomy, however, requires that patients be competent, and their level of competence is dependent on their psychosocial environment.¹ It is thus necessary for the student to be able to **balance paternalism** and respect for autonomy in different scenarios.

As described by Lerner and Caplan, bioethical education and discourse must be used to “historicize but not minimize past ethical transgressions” so as to emphasize why and how such events happened.¹⁷ Just as students are implored to evaluate academic research in the context of a priori and retrospective biases, so deconstructing history can reveal how complex historical circumstances can lead to experimentation that is unethical in hindsight. Lobotomies, for example, are viewed today as barbaric, but before the advent of antipsychotic medications they were believed to be the best last-resort option for patients who suffered immensely from psychosis.¹⁷ Similarly, the infamous US Public Health Service Syphilis Study at Tuskegee, which knowingly denied accepted treatment to poor African-Americans with syphilis, arguably was ethically justified, at least early in the study when, prior to the advent of penicillin, treatment was prohibitively expensive for many study participants, such that these participants might have been no worse off had they not participated. By arming students with this knowledge and making them aware that the fallacy of Whig history (that society becomes morally progressive over time) also applies to medicine and that past transgressions can be regarded as at least explicable, if not excusable,¹⁷ students can critically evaluate how best to obtain informed consent.

Discussion

Empathy is poorly defined, and interventions to cultivate empathy have failed to translate into clinical practice. It has been shown that undergoing communication-enhancing interventions does not improve medical students' attitudes toward patient centeredness,⁵ and it has been posited that unprofessional students can “fake” professional behavior in exam settings.¹⁸ We do not disagree with the difficulty of empathy education. Given the brief overview provided of complex factors that go into the patient-clinician relationship, we argue that undertaking shared decision making with

patients is complex to the point of requiring cumulative and longitudinal experience that is outside the scope of many studies. We suggest a strategy by which educators introduce cultural and historical perspectives as early as possible in medical training so that each student can be exposed to many social and cultural worlds over time beyond their own social and cultural bubble. This greater awareness, in turn, would help each student understand patients' preferences and decisions, thereby laying the groundwork for shared decision making. Before interventions can truly take hold, we must first ensure that all members of the medical profession understand that the factors discussed in this paper exist.

It can be argued that the addition of empathy training places an unrealistic burden on trainees struggling to demonstrate competency at a time when compassion fatigue and burnout are garnering attention. We argue that teaching empathy in medical education would best support patient-centered care. As our profession evolves, physicians and educators must also consider the many factors that contribute to patient health beyond medicine. To ignore these would be a disservice not just to our patients, but also to future medical professionals who have the right to be aware of the factors that complicate care.

Conclusion

In order for new resident physicians to overcome the many frustrations that might be involved in the shared decision-making process, medical educators must cultivate empathy early in students' careers. Given the complexity of patient backgrounds in conjunction with institutional and clinician bias and socioeconomic disparities, it is vital that medical students understand the sociodemographic and cultural factors that influence patients' preferences and decisions regarding health care. Only then can the student begin to apply the knowledge of medicine by focusing it through the lens of the patient. And only when the physician's medical training and the patient's unique real-life experiences are bridged can the patient be truly informed and the physician and patient begin to have effective and efficient conversations.

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STATE OF THE ART AND SCIENCE

How Will Artificial Intelligence Affect Patient-Clinician Relationships?

Matthew Nagy, MPH and Bryan Sisk, MD

Abstract

Artificial intelligence (AI) could improve the efficiency and accuracy of health care delivery, but how will AI influence the patient-clinician relationship? While many suggest that AI might improve the patient-clinician relationship, various underlying assumptions will need to be addressed to bring these potential benefits to fruition. Will off-loading tedious work result in less time spent on administrative burden during patient visits? If so, will clinicians use this extra time to engage relationally with their patients? Moreover, given the desire and opportunity, will clinicians have the ability to engage in effective relationship building with their patients? In order for the best-case scenario to become a reality, clinicians and technology developers must recognize and address these assumptions during the development of AI and its implementation in health care.

AI Uncertainty

Artificial intelligence (AI), defined as the capability of a machine to imitate intelligent human behavior,¹ promises to become an innovative and disruptive force in medicine. Emerging technologies will have the capacity to extract and analyze clinical and scientific data in a fraction of the time it would take a human physician. For example, a radiologist might view hundreds of thousands of scans throughout her career, while a deep-learning algorithm could incorporate data from millions of scans instantaneously to process an image and highlight abnormalities.² Similarly, a future oncologist might utilize AI to analyze scientific literature and identify personalized treatments for specific mutations in a patient's tumor.^{3,4} While most experts believe AI will facilitate improved technical care for patients in the near future, it is uncertain how these advancing technologies will affect the relationship between patients and clinicians.^{3,5}

A healing patient-clinician relationship is formed by a patient's and clinician's mutual trust, respect, and commitment, which relationship continues to strengthen as rapport and mutual understanding develop.⁶ Establishing and maintaining this healing relationship is central to providing effective care, and strong relationships can improve both a patient's health care experience and clinical outcomes.⁷ According to the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, building and maintaining these relationships is also essential to improving

the overall health care system.⁸ Without the trust that emanates from a healing relationship, patients can experience anxiety, frustration, and second-guessing. Given the importance of building and maintaining these relationships, the integration of emerging technologies into medical care should aim to promote rather than diminish the relationships between clinicians and patients.

Whether AI will harm or help the **patient-clinician relationship** in the future remains uncertain. Some experts argue that incorporating AI into medical care will enhance the patient-clinician relationship by off-loading tedious work, thus allowing clinicians to spend more time directly engaging with their patients.⁹ Additionally, AI might provide richer and more specific information about an individual patient's treatment options and expected outcomes. Such personalized data could allow clinicians to engage their patients more meaningfully in shared decision making. Others, however, worry that the clinician's role might become obsolete if patients value the increased diagnostic and treatment accuracy offered by AI more than they value human interaction.³ Even if patients still value the humanistic aspects of medical care, some believe these relational needs might soon be met by machines, such as **conversational agent systems**.³

Even if AI fulfilled its promise of increasing efficiency and treatment personalization, it might not lead to improvements in the patient-clinician relationship. The link between successful implementation of AI in health care and maintaining or improving the patient-clinician relationship relies on several assumptions. In this paper, we will highlight 3 key assumptions (though more may exist) that underlie the optimistic view that AI will improve the healing patient-clinician relationship. If these assumptions are not acknowledged and addressed now, then novel technologies might exacerbate, rather than mitigate, current challenges to these relationships.

Off-loading Tedious Work

American clinicians spend appreciable time analyzing patient data, developing a differential diagnosis, and evaluating potential treatment options.¹⁰ Despite this effort, the vast amount of clinical and research data available has long surpassed physicians' cognitive processing capabilities,¹¹ leading to arduous yet uncomprehensive assessments. Once the clinician eventually reaches the patient's room, his attention is further divided by tedious charting responsibilities.

Future AI technologies will likely decrease the clinician's tedious charting responsibilities both before, during, and after the patient encounter. Rather than the clinician spending an inordinate amount of time analyzing data related to a patient's condition, AI could potentially sift through millions of patient-specific data points and provide a **differential diagnosis, prognosis, and treatment options** both more quickly and more accurately than clinicians. During the clinical visit, voice recognition technology might eliminate manual note entry into the electronic health record.¹² Similarly, clinicians might be able to order medications or tests verbally while in conversation with the patient, allowing for fewer peripheral tasks and greater attention to the patient's needs.

By decreasing arduous work and time spent analyzing data, AI presumably will facilitate improved information exchange and shared decision making between patients and clinicians.^{9,13} While technical advances might decrease some analytical and administrative demands, AI could also increase the interpersonal demands of patient care. Instead of one or two treatment options to consider for a given disease, AI might

offer six or seven possible treatments, along with a wealth of information regarding prognosis and adverse effects. Additionally, many patients might experience an initial distrust of AI, especially since the “black-box” nature of some technologies will make it impossible for the clinician to explain how many recommendations are generated by the algorithm.¹⁴ As such, the clinician might spend time explaining and vouching for the AI system’s recommendations to patients. Moreover, an increase in available information necessitates more time to educate the patient, elicit patient values, and come to a shared decision.¹⁵ Thus, although many current tasks of clinical care might be off-loaded to an algorithm in the future, the time demand and intentional effort required to provide high-quality clinical care might not decrease and could in fact increase.

Efficiency and Healing

Although time might be recouped from administrative duties by the implementation of AI technologies, structural and personal barriers might hinder clinicians from using this time to further develop their relationship with their patients. For example, the time allotted for each patient visit has remained relatively stable over time, yet the complexity of cases and number of administrative tasks has increased.¹⁶ This overstretched clinical environment has been driven, in part, by the business model of medicine. Facilitating longer visits would necessitate either a decrease in the volume of patients seen in clinic or an increase in the number of clinicians hired, both of which would decrease profit margins.¹⁷ Accordingly, if AI decreases the time required for a patient visit, the health care system might respond by increasing the volume of patients seen per day rather than allowing time for relationship development and shared decision making. Perhaps administrators might determine that AI-driven efficiency allows clinicians to see 25% more patients per day. Physicians could end up with schedules that are more tightly packed, with less time allotted for each visit.

Even if the clinical load remains stable, personal barriers might prevent some clinicians from engaging with their patients to develop trust and elicit their values regarding goals of care. Highly personal and emotional communication can make some clinicians uncomfortable,¹⁸ although one study found that many patients with serious illness prefer their clinicians to provide sensitive, acknowledging, and supportive statements.¹⁹ As the second author and colleagues have previously argued, such personal and emotional communication should be viewed as a complex clinician behavior that is influenced by cognitive, social, economic, and cultural factors.²⁰ In Western medical contexts, physicians are often trained to remain emotionally detached in order to maintain scientific and medical objectivity. Some clinicians worry that being fully emotionally present could be characterized as unprofessional or might lead to personal distress.²¹ Alternatively, other clinicians might not view such value-laden discussions as their responsibility, or they might prioritize other tasks.²² Even if novel technologies provide clinicians with more time and richer data sets, persistent personal barriers can impede the development of healing relationships. As such, future work should aim to address personal and professional barriers that can hinder the development of a trusting and open patient-clinician relationship.

Engaging Patients

If we assume that AI technologies will provide clinicians with more time and richer patient data, and we further assume that clinicians will be highly motivated to engage in relationship building, another critical assumption remains: clinicians will be able to engage meaningfully in these relationship-building activities. We believe that most clinicians genuinely care about their patients and want the best for them. Thus, one

might assume that clinicians with additional time and sufficient motivation would translate these intentions into fruitful conversations aimed at better understanding patients' beliefs and values in order to provide the best individualized care. A limited skill set, however, can trump time and motivation. For example, many clinicians report low confidence in their ability to engage in difficult or emotionally charged conversations as a reason for not engaging in shared decision making.²³ Similarly, some clinicians avoid discussing their patient's psychosocial concerns because they are unsure how to respond.²⁴

Improving clinicians' communication and social skills will likely require multiple approaches, such as admitting medical students partly on the basis of their social skills and capacity for empathy, early and continued training in communication and relationship building, increased attention to preventing or addressing burnout and moral distress, and opportunities for continued feedback on communication skills. Determining the best approach is an empirical question that is beyond the scope of this paper. However, continued work in this area is needed to maximize the positive benefit of future technologies in health care.

Conclusion

Advanced AI technology has the potential to improve the efficiency and accuracy of medical care, but, as Francis Peabody pointed out in 1927, "The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal."²⁵ The healing patient-clinician relationship is an essential aspect of health care. Without forethought and planning, the implementation of new technologies might diminish the patient-clinician relationship in the name of efficiency, accuracy, or cost reduction. As such, clinicians, technology developers, administrators, and patient advocates should take steps to maintain the centrality of the healing relationship in medical care as AI technologies are developed and further integrated into the health care system.

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POLICY FORUM: PEER-REVIEWED ARTICLE

Should Decision Making Be Shared in High-Risk Pediatric Heart Donation?

Efrat Lelkes, MD, Angira Patel MD, MPH, Anna Joong, MD, and Jeffrey G. Gossett, MD

Abstract

This article considers complexities of shared decision making in pediatric heart transplantation and suggests that decisions about pediatric heart transplantation should be shared between a clinical team and parents. This article also considers goals of shared decision making involving Public Health Service increased-risk donors and recommends policy changes to strengthen decision sharing.

Need for Pediatric Donor Hearts

Heart transplantation (HTx) is the standard of care for children with end-stage heart failure, with approximately 500 pediatric heart transplants performed annually in the United States.¹ A significant shortage of available organs exists, however, leading to long wait list times and significant morbidity. According to the Organ Procurement and Transplantation Network (OPTN), the average waiting time on the list for a pediatric patient from 2007 to 2014 was 115 days, with children ages 1 to 5 years waiting an average of 139 days (OPTN database). Indeed, of the 4392 children listed for HTx during this time frame, 457 (10.4%) died prior to HTx and still others were removed from the waiting list because they became “too sick to transplant.”

In this article, we discuss the complexities and nuances of the decision to proceed with pediatric HTx, and we maintain that this decision should be a truly shared decision between the medical team and the parents of a pediatric patient. We argue that the rules governing discussions about increased-risk donors result in a decreased utilization of donors in a system in which more pediatric donors are needed, despite the negligible risk of infectious transmission.^{2,3} We instead suggest a systematic change in which nondissent is used when increased-risk donors are involved.

Increased-Risk Donors

Limited **organ availability** makes increasing utilization of donor hearts critically important. In 2004, the United Network for Organ Sharing (UNOS) labeled organ donors Public Health Service increased-risk (PHS-IR) donors if they met Centers for Disease Control and Prevention criteria for “high-risk” behaviors (see Table). This donor category is intended to identify donors who, despite being negative for infections such as HIV and

hepatitis on all serologic testing, may have become infected during the short window of time when they could have acquired the disease but tests could be negative. Based on OPTN data, in 2018, 10% of pediatric and 35% of adult donors were labeled “increased risk” for transmission of HIV, hepatitis B (HBV), or hepatitis C (HCV) (OPTN database).

Table. 2013 US Public Health Service Increased Risk Guidelines^a

“MSM [men who have sex with men] in the preceding 12 months
“Non-medical injection drug use in preceding 12 months”
“People who have had sex in exchange for money or drugs in the preceding 12 months”
“People who have had sex with a person known or suspected to have HIV, HBV, or HCV infection in the preceding 12 months”
“Women who have had sex with a man with a history of MSM behavior in the preceding 12 months”
“People who have had sex with a person who had sex in exchange for money or drugs in the preceding 12 months”
“People who have had sex with a person who injected drugs by intravenous, intramuscular, or subcutaneous route for nonmedical reasons in the preceding 12 months”
“A child who is \leq 18 months of age and born to a mother known to be infected with, or at increased risk for HIV, HBV, or HCV infection”
“A child who has been breastfed within the preceding 12 months and the mother is known to be infected with, or at increased risk for, HIV infection”
“People who have been in lockup, jail, prison, or a juvenile correctional facility for more than 72 consecutive hours in the preceding 12 months”
“People who have been newly diagnosed with, or have been treated for, syphilis, gonorrhea, Chlamydia, or genital ulcers in the preceding 12 months”
“People who have been on hemodialysis in the preceding 12 months (hepatitis C only)”
“When a deceased potential organ donor’s medical/behavioral history cannot be obtained or risk factors cannot be determined, the donor should be considered at increased risk for HIV, HBV, and HCV infection because the donor’s risk for infection is unknown”
“When a deceased potential organ donor’s blood specimen is hemodiluted, the donor should be considered at increased risk for HIV, HBV, and HCV infection because the donor’s risk for infection is unknown”

^a Adapted from Organ Procurement and Transplantation Network.⁴

Currently, transplant programs are mandated to inform candidates and families about the general risks of disease transmission from organ donors, obtain their permission to consider PHS-IR donors, and then document informed consent (IC) at the time of HTx if the organ is from a PHS-IR donor. Despite a widely publicized adult case of transmission of HIV and HCV from a donor in 2007,⁵ there are no reported cases of donor-derived HIV, HBV, or HCV infections in pediatric solid organs.^{4,5,6,7} The overall risk of an IR donor with negative nucleic acid testing actually transmitting HIV is estimated to be 0.04 to 0.49 per 10 000 donors.⁸ Accepting a PHS-IR organ has not been shown to adversely impact survival of either pediatric or adult heart transplant recipients.^{2,9,10} Nevertheless,

the waiting time for children often exceeds 6 months, with a wait list mortality of more than 10%.¹

Despite the negligible risk of infectious transmission from PHS-IR donors,^{2,3} most grafts from donors that are designated as IR are declined.¹¹ Indeed, heart transplant providers themselves have varied opinions about accepting PHS-IR hearts. (Depending on why the hearts are listed as PHS-IR, 46% to 98% of heart transplant providers would accept these grafts.¹²) And parents are more likely to decline these grafts.¹¹ Not utilizing grafts from these donors leads to a longer wait time, which in turn results in increased mortality risk.¹³ Thus, by excluding PHS-IR donors, the risk of a child not surviving until HTx increases without a correlative improvement in outcome.

Decision Sharing With Pediatric Patients

The decision to pursue HTx for a pediatric patient is best done via a shared decision-making (SDM) approach in which clinicians and parents “make decisions together using the best available evidence” when faced with the task of making decisions and in which parents “are supported to consider options, voice their preferences, and make informed decisions.”¹⁴ Pursuing HTx necessitates agreement and investment by the interdisciplinary medical team and the family. Reaching this agreement involves discussion of myriad complex aspects, each with a unique risk-benefit profile, including death on the waiting list and death after HTx. All of these aspects are discussed as part of the overarching SDM process of opting for (or against) HTx.

Of all of the risks in the decision to pursue HTx, only PHS-IR is singled out for a separate consent at time of organ acceptance,¹⁵ which we believe undermines SDM. It is likely that, by enforcing a separate consent, the OPTN intended parents to explore the implication of a PHS-IR donated heart (the implication being that, in fact, the outcomes are not different but wait times are longer if declined) during the time-sensitive period when they evaluate an offer. However, OPTN’s singling out PHS-IR hearts for a separate consent forces parents to decide in isolation from the clinical expertise of the medical team. This procedural and technical choice discredits the earlier collaborative process in which the decision to proceed with HTx was made.^{16,17} It falsely places the choice to accept a PHS-IR donor heart in an SDM context when it actually belongs within the informed consent model. Specifically, we argue that the choice to proceed with a PHS-IR donor heart is best made via informed nondissent, thus protecting the role of SDM in HTx.^{18,19}

No to Separate Informed Consent

Pediatric patients are thought to have **developing autonomy** and do not give consent for their own medical care; rather, parents provide informed consent.²⁰ Parents do so by acting as surrogate decision makers using the best-interest standard, as they have a fiduciary responsibility to their child to maximize his or her well-being. This responsibility is highlighted in parents’ decision to choose HTx for their child, a decision dictated by their belief in their obligations to their child and respect for their child’s future personhood.

Parents’ decision to pursue HTx is a difficult one and should occur in the context of a rigorous SDM model.²¹ Parents must decide with the health care team if HTx is right for their child, but not necessarily which heart is the best. At the time of listing, disclosure and **counseling of families** about risks, including risks of potential disease transmission from the donor, is a necessary and important part of the SDM approach. Once the

decision has been made to pursue HTx, the transplant providers decide whether specific donor offers are appropriate for a patient. For example, the transplant team will decide whether the upper age limit of the donor or anticipated longer ischemic times (which may result in a worse outcome) are relevant for a given patient and leave these decisions out of the SDM process.²² However, for PHS-IR donor hearts, for which outcomes are equivalent to standard risk donor hearts,² the requirement of additional IC negates the nuanced assessment and responsibility of the providers. Although a transplant team may find a heart acceptable and determine it to be from a “good” donor, the parents’ decision to not accept a PHS-IR heart can overrule this assessment. To do so harms pediatric patients by increasing wait times and risk of death, since there is no evidence of a tangible difference in outcomes with these grafts compared to standard-risk grafts—not only in infectious risks, but also in survival.^{2,9,10}

Following the publicized case of infection transmission from a serologically negative donor in 2008, Halpern et al eloquently argued that standardization of the disclosure of risk to patients awaiting HTx was needed but warned against relaying organ-specific risks: “the disclosure of organ-specific risks may not increase the ability of patients to make welfare-promoting decisions” because “some patients might select organs not on the basis of actual risk,” and “finally, because the organ-specific disclosure of risk requires extra time precisely when time is at a premium, it could prevent the optimal use of the organ supply.”⁷ The UNOS PHS-IR policy, in an attempt to standardize disclosure, instead emphasizes the organ-specific risks.⁴

With improved screening for donors, which is currently being implemented, the risk of contracting HIV, HBV, and HCV from serology-negative donors remain negligible. The risk is akin to minimal risk of transmission of infections with blood product transfusions²³ compared to potentially life-threatening risk of withholding transfusions. Given the evidence that patients who don’t receive an organ have higher rates of mortality than if they receive one from a PHS-IR donor,²⁴ we propose that this policy be modified to respect an overarching shared decision that parents make with their transplant team to pursue HTx for their child.

Proposed Policy Reform

We argue that UNOS and OPTN should reverse the policy that transplant programs must obtain IC at the time of HTx for serology-negative donor hearts with PHS-IR risks identified pretransplantation. Instead, we propose a model of what Kon describes as “informed non-dissent.”^{18,19} In this model, the discussion of PHS-IR donors is integrated into IC for HTx. When parents initially consent to HTx, physicians should disclose the risks of infection transmission from the donor, including but not limited to HIV and hepatitis, and explain the minimal risk of a false negative result associated with PHS-IR donors.²⁵ Equally important is the careful discussion of the context of the dramatically greater risk of mortality from declining these organs. We argue it should be determined at the time of consent if a parent declines the use of grafts from PHS-IR donors, and this decision (which can be revisited as a patient awaits a heart and may be getting sicker) would be part of the HTx team’s determination of which donor heart may be appropriate for the child. This policy reform thus would allow for veracity about what PHS-IR indicates while respecting the autonomous decision of parents to pursue HTx for their child. Resultantly, the decision making would be more comprehensive and truer to the SDM model.

Conclusion

In this proposed policy reform for pediatric HTx, we argue that SDM should be a comprehensive approach at the time of listing for HTx. The necessity for a separate consent at the time of organ offer gives the appearance of higher import and implies that the onus is on the parents—not the transplant team—to make this decision. The weightiness of this responsibility may undo the entirety of the SDM process. If a family and the medical team have decided—together—to pursue HTx for a pediatric patient, the goal for that patient should be to find an acceptable donor as soon as possible. Given the number of children who die each year awaiting HTx, we should remove barriers and increase the utilization of what are ultimately “good” organs. Changing the policy for PHS-IR donors to consent at the time of listing, and thereby honoring SDM for HTx, is a necessary step to improve the mortality of patients awaiting a heart transplant.

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MEDICINE AND SOCIETY

Epistemic Authority and Trust in Shared Decision Making About Organ Transplantation

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Abstract

Patient epistemic authority acknowledges respect for a patient's knowledge claims, an important manifestation of patient autonomy that facilitates shared decision making in medicine. Given the scarcity of deceased donor organs, transplantation programs state that patient promises of compliance cannot be taken at face value and exclude candidates deemed untrustworthy. This article argues that transplant programs frequently lack the data to make this utilitarian calculation accurately, with the result that, in practice, the psychosocial evaluation of potential transplant candidates is discriminatory and unfair. Historically excluded candidates, such as patients suffering from alcohol use, have turned out to benefit highly from transplantation. Transplant programs should tend to trust patients when they claim to be good potential organ stewards, thereby respecting patient autonomy, advancing justice, and saving more lives.

Epistemic Authority Is Foundational

Epistemic authority is granted when an agent is trusted and his or her knowledge claims are respected by outside parties.¹ Health care usually prioritizes the physician's epistemic authority. The physician is a highly trained expert making a medical assessment of the patient, and the patient's willingness to consider the physician's assessment is a critical component of any patient-physician interaction. Presumably, the patient visits the physician because he or she values the clinician's expertise—that is, the physician's epistemic authority.

Respect for patient autonomy is another key pillar of the patient-physician relationship in Western clinical medical ethics. In the shared decision-making framework, physicians offer expertise and judgment, and patients bring their own values and preferences to the collaborative decision-making process. We assert that respecting patient autonomy calls for the physician to grant the patient a degree of epistemic authority regarding claims of self-knowledge. To build a strong patient-physician relationship, the physician must consider the patient reliable and trustworthy until proven otherwise. For example, if a physician believes a patient has not been adherent to a treatment, the physician might conclude that the patient has “failed” a treatment. Trusting the patient calls for

the physician to first ask, “Why did this treatment fail the patient?,” not, “Why did the patient fail the treatment?” If the physician does not trust the patient, the patient-physician relationship devalues patient autonomy and becomes more paternalistic.

We consider the role of patient **epistemic authority** when a patient is evaluated by the organ transplant team prior to being placed on the waiting list. During this paternalistic process, the reliability claims of potential candidates are repeatedly challenged on utilitarian grounds during an intense psychosocial evaluation.^{2,3} Transplant providers believe this high level of scrutiny is justified to select good organ “stewards” to make best use of scarce deceased donor organs and save the most lives. We argue that current organ transplantation system incentives encourage unwarranted bias against many patients with psychosocial risk factors and paradoxically lead to organ allocation decisions that do not maximize utility. We conclude that distrust of patient epistemic authority reduces patient autonomy, vitiates utilitarian outcomes, and leads to injustice.

Utilitarian Frameworks in Transplant Ethics

Hundreds of thousands of patients have end-stage organ failure in the United States and are potential candidates for transplantation. Heart failure kills more than 300 000 Americans a year,⁴ and approximately 750 000 patients are on hemodialysis for end-stage kidney disease.⁵ Currently, a fortunate 124 000 or so patients are on the transplant waiting list,⁶ which has not been shortened despite an increase in the donor supply from the opioid epidemic.

Two major federal regulatory actions shape the **organ allocation policy** landscape and define its primarily utilitarian ethical framework. First, the Centers for Medicare and Medicaid Services imposes strict posttransplant graft and patient survival benchmarks that transplant programs must meet to remain in operation.⁷ Centers are frequently penalized or shut down due to these requirements; more than 20 lost Medicare funding and most of these were shut down; an additional 40 were placed in a probational status during the last 10 years alone.⁸ Second, federal rules for organ allocation policy calls for wait-listed candidates to meet standardized minimum listing criteria and be ranked “in order of decreasing medical urgency.”⁹ Synthesizing the high posttransplant survival benchmarks with the prioritization of medically urgent candidates, the effective ethical framework is primarily utilitarian, ie, focused on maximizing the medical benefit of each transplant. Equitable access is also a consideration (eg, increased priority for highly immunologically sensitized patients with few potential compatible donors), but it is secondary to utility. Finally, federal organ allocation rules intend to minimize **geographic disparities**,⁹ but these mandates are largely ignored in current organ-specific allocation policies or their implementation.^{10,11,12,13} More complete multiprinciple ethical frameworks for allocation have been proposed that explicitly incorporate conceptions of equal access and justice (eg, allocating organs to younger people so that they can live a complete life).^{14,15,16} However, in the current policy framework, these considerations are secondary to ensuring that each organ transplant results in a tangible, sustained medical benefit for the recipient.

Reliability in Candidate Selection Processes

Candidates for transplantation undergo a rigorous evaluation by transplant programs. Programs have standardized **candidate selection criteria** that are intended to exclude candidates at higher risk of postoperative mortality or complications. Candidacy restrictions are distinct from and in addition to strict contraindications to transplantation. For example, lung transplantation is contraindicated in patients with

left-ventricular failure, as it would worsen their condition due to lack of lymphatic drainage in the transplanted lungs.¹⁷ In contrast, lung transplantation is not strictly contraindicated in patients with chronic kidney disease.¹⁷ However, renal dysfunction is associated with significantly worse outcomes posttransplantation,¹⁸ and thus the strict posttransplant survival benchmarks might incentivize programs to exclude these patients from transplantation.

These candidacy criteria extend beyond objective medical comorbidities. Strict adherence to antirejection medication is necessary for a complication-free and low-risk posttransplant course. Therefore, programs impose nonmedical psychosocial candidacy criteria based on detailed psychiatric and social evaluation by a mental health professional.^{2,3} A potential organ transplant candidate must convince the transplant team that he or she has adequate social support and the ability to adhere to treatment to meet whatever threshold has been set by the transplant team. Psychosocial requirements for organ transplant candidacy directly challenge patient epistemic authority regarding claims of reliability and organ stewardship, decidedly shifting the balance of decision making towards the transplant providers. Transplant programs are unilaterally empowered to tell candidates, “We don’t trust that you will be reliable posttransplantation,” and to cut off access to the waiting list.

Sources of Bias

Relying on a utilitarian notion of medical benefit of transplantation implies that a precise utilitarian calculation of benefit is possible. The most common metric employed in organ transplantation is survival benefit, defined as the improvement in survival expected from transplantation compared to remaining in a state of end-organ failure.^{19,20,21,22,23} In the utilitarian framework, in order for a psychosocial requirement for transplantation to be justified, it must have a clear relation to net survival benefit.

However, the evaluation of psychosocial factors is compromised due to the underlying biases of the transplantation team. Multiple studies have revealed evidence of systematic bias on the basis of race in accessing transplantation. Among “very healthy” patients with isolated single organ failure and no medical comorbidities, non-Hispanic white patients have substantially higher rates of renal transplantation than minority groups.²⁴ When liver allocation relied on subjective inputs from transplant providers, a significant disparity in transplantation rates existed between African-American and white candidates that completely resolved with the implementation of the objective Model for End-stage Liver Disease (MELD) score.²⁵ Moreover, African-American patients are less likely to be given information about kidney transplantation at dialysis centers and more likely to be found “psychologically unfit” for transplantation.²⁶

The best available tool for systematic assessment of psychosocial factors, the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT),² can predict social support system failure and episodes of acute organ rejection.²⁷ However, the SIPAT was tested and validated in a predominantly white and well-educated patient population; although recently translated into Spanish,²⁸ its performance in diverse patient populations is unknown. Importantly, the SIPAT has not reliably predicted posttransplant survival in any patient population.²⁷ Without proper design, prediction models can exacerbate disparities driven by biases present in the data, depending on how those inaccurate models are used.²⁹ The evidence we have discussed suggests that psychosocial risk cannot be accurately assessed based on clinicians’ judgment and

existing screening tools. Biases lead to inaccurate utility calculations and injustice from unacceptable discrimination.

In addition, existing *de facto* systems for predicting the benefit from transplantation do not accurately account for the utility benefit of transplanting patients with increased psychosocial risk. Candidates with higher psychosocial risks are often the sickest and have very high expected mortality without transplantation.³⁰ This group thus has a large expected benefit from transplantation, despite the increased risk the psychosocial factors pose in the posttransplant period, as was demonstrated when transplant centers in France broke with an arbitrary “6-month abstinence” rule and began performing early liver transplantation for active drinkers with severe acute alcoholic hepatitis.³⁰ Recipients experienced a 6-month absolute survival benefit of over 50%; in contrast, the average US liver transplant recipient has no significant absolute survival benefit at 6 months. Low rates of recidivism posttransplantation were observed, and the limited posttransplant drinking that did occur was not substantial enough to mitigate the long-term survival benefit.³¹ Clearly, any utilitarian calculation would support broadening liver allocation to active drinkers based on these data.

Roles of Financial Incentives

The paternalism that transplant programs display with respect to patient epistemic authority may be driven by reasons without a solid ethical justification. While the federal rules are clear on medical urgency being prioritized, candidacy criteria are poorly designed to achieve this goal. Transplant programs are incredibly lucrative. A heart or lung transplant bills for over \$1 million,³² so program shutdown for poor posttransplant outcomes leads to enormous economic losses for providers and hospitals. Recent media reports have illustrated that programs will go to tremendous lengths to prevent recipient deaths within a year.⁸ With large incentives to keep the transplant program busy and minimize postoperative costs, transplant programs are driven to select candidates with the highest expected posttransplant 1-year survival, regardless of the absolute survival benefit from transplantation for the patient. These incentives lead to gaming of waiting list rankings,^{33,34,35} with the result that they likely contribute to overly restrictive social criteria for transplantation as well. Because higher medical urgency is correlated with increased survival benefit,²³ centers cherry-picking healthy patients to maximize posttransplant 1-year survival are prioritizing profit over the utilitarian intent of the transplant system rules.

Conclusion

To be clear, we are not arguing for transplant teams to completely ignore psychosocial factors and write their patients blank epistemic checks. The current utilitarian ethical framework for organ transplantation certainly allows for withholding transplantation from candidates with obvious and insurmountable social limitations that would make benefit from transplant unlikely. The basic major transplantation society guidelines are reasonable in recommending abstinence from alcohol and illicit drugs, adherence to medication, absence of uncontrolled psychiatric disease, and presence of a strong social support system.^{17,36}

However, both utilitarianism and justice demand that organ transplant providers rely on patient epistemic authority for reliability claims fundamental to candidacy. In the absence of clear unbiased data suggesting otherwise, transplant programs should trust patient claims regarding social support networks and commitment to adherence. When disqualification based on social factors is pursued, best use of organs demands that the

threshold be high and supported by rigorous empirical evidence of low transplant effectiveness. If transplant programs want to save the most lives, they should learn to trust their patients and engage in true shared decision making.

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MEDICINE AND SOCIETY

What's the Role of Time in Shared Decision Making?

Alexander T. Yahanda, MS and Jessica Mozersky, PhD

Abstract

Shared decision making (SDM) is a desirable process and outcome of patient-clinician relationships. Ideally, patients and clinicians have sufficient time to engage in SDM. In reality, time is often insufficient. This article explores time as a barrier to SDM, alternative ways clinicians can think about time, and steps they can take to have fulfilling SDM interactions despite time constraints. Although discussions of time typically focus on time quantity, redirecting attention to the ethical significance of time in establishing patient-clinician relationships suggests the importance of also considering time quality.

Time as a Barrier

Shared decision making (SDM)—the process by which clinicians and patients work together to make health care decisions that align with patients' goals, preferences, and values—is an ideal outcome of patient-clinician relationships.¹ Yet multiple **potential barriers** obstruct SDM in real-life clinical practice.^{2,3,4,5,6} Chief among these is time, particularly the amount and quality of face-to-face time clinicians and patients spend together. Studies have shown that both patients and clinicians view time constraints as a frequent and substantial barrier to SDM.^{7,8,9,10,11} Prevailing sentiment among clinicians and patients is that there is an inherent tension between time and SDM.

Clinicians face substantial time pressure to efficiently accomplish clinic visits or other patient-related duties, making their time a valuable and scarce resource. They routinely deem the quantity of time they have with patients inadequate,^{12,13} and this perceived time shortage is compounded by mounting **burdens of documentation** and other administrative duties.^{12,13} In fact, physicians' satisfaction with the perceived amount of time they have with each patient has decreased over the past few decades.^{12,14,15,16,17} Clinicians perceive that truly fulfilling requirements for SDM necessarily adds time to encounters with patients.⁸ Moreover, differing opinions exist among clinicians regarding the value of engaging patients in SDM, even though facilitating SDM has been associated with improved **patient outcomes** and quality of life.^{18,19,20,21,22}

Patients, too, are aware of clinicians' busy schedules, which can affect the extent to which they actively participate in decision making.²³ If patients view SDM as requiring more time, they might consider it less important than other parts of a clinic visit, and the

importance they give SDM can diminish further when faced with a clinician who seems pressed for time. Patients might elect not to elaborate on their goals and preferences for any number of reasons, including a desire to take up less time, a feeling of being rushed or pressured to speak succinctly, and not wanting to ask too many questions.^{23,24} Conversing with clinicians under time pressures can also alienate some patients who feel that they are not being treated as individuals.²³

Does SDM Add Significant Time?

Both patients and clinicians desire more time during visits, and longer encounters have been shown to increase patient satisfaction.²⁵ That said, a number of studies indicate that SDM does not have to add prohibitive length to patient encounters.^{26,27,28,29,30} A study of SDM discussions with surgical patients showed that reaching appropriate levels of SDM could be achieved in a median time of 17.8 minutes vs 15.4 minutes for meetings that failed to reach what the authors deemed a “reasonable minimum” amount of SDM.³¹

Efficient SDM might be achieved when appropriately tailored questions or **decision aids** are used to aid SDM. Decision aids are standardized, validated tools that can be used to better facilitate SDM by augmenting—rather than replacing—interpersonal exchanges.³² Decision aids can come in several different forms—for instance, printed text, audio recordings, or videos—and assist patients in personalizing uncertainties and the risks and benefits of interventions.³²

Furthermore, asking the same questions of every patient has been shown to increase patient understanding and enhance SDM without increasing the duration of encounters.³³ Two Cochrane review articles examining uses of decision aids to facilitate SDM found that they can improve communication, information sharing, and risk assessment, thereby helping patients feel more satisfied with their choices, knowledge base, and decisions.^{34,35} Importantly, across all studies, decision aids’ use added a median of 2.6 minutes to clinical encounters.^{34,35}

Quality vs Quantity of Time

Notably, discussions of SDM and time tend to consider time in terms of objectively calculated quantities.^{26,28,31,35} By quantitative measures, SDM requires more time than might be available. Theoretically, by substantially increasing the amount of time per day devoted to patient care (for instance, by scheduling longer clinics or by compelling physicians to increase the number of daily rounds), clinicians would almost always have adequate time for SDM. This solution, however, is not practical given the myriad obligations that clinicians and patients have. Additionally, attempting to make patients’ time with clinicians more efficient through methods such as revamping schedules and scheduling systems, creating algorithms to provide optimal time for encounters with different patients, or giving patients “homework” between interactions is logistically challenging.

An alternative is to focus on ways clinicians can enhance the *quality* of time they spend with patients. This approach could help clinicians meet ethical obligations to patients without adding significant time to encounters. For example, thoroughly structuring communication to be patient centered, such that clinicians actively listen to patients; solicit questions, fears, and goals; and focus on emotional dimensions of patients’ illness experiences could help emphasize quality and mitigate perceptions of how time is limited in quantity. SDM, as we describe below, can be accomplished by adding a few

minutes. Although clinicians may feel as though they do not have sufficient time for each patient, increasing the quality of their time with patients can augment the SDM process by allowing for stronger relevant discussions within the same time limits.

How to Increase Quality

Clinicians can draw on decision aids, among other methods, to improve the quality of time they spend with patients and improve patient understanding of complex clinical information, which improves both SDM during a clinical encounter and patients' adherence to treatment plans.³⁶ Nevertheless, clinicians should not become overly dependent on decision aids, as patients still prefer organic interpersonal discussions over those driven by decision tools.³⁷ Clinicians can also streamline conversations by asking a standard set of questions of each patient or by directly asking the patient to clarify the main reason for their visit.^{38,39,40,41} One study found that a patient's purpose for visiting a physician was discussed in only 36% of encounters.³⁸ Since eliciting goals is part of SDM, this finding suggests that SDM was taking place in fewer than 36% of visits.

The need to quickly learn about patients' goals or preferences should be balanced with the need to address each patient as an individual. Improving how clinicians listen to patients is another critical step in including patients in decision making, and this skill should be emphasized in education and training. In one study, clinicians interrupted patients after a median time of 11 seconds, which was partially due to their feeling rushed.³⁸ Since most patients prefer to play active roles (variously defined) in making health decisions, it is crucial that clinicians learn streamlined approaches to managing the quality and quantity of time devoted to SDM.^{42,43,44}

Clinicians should cultivate awareness of how their subtle forms of communication and body language, as well as their words, might be perceived by patients. For example, clinicians should verbally convey their recognition of the value of a patient's time, apologize for tardiness, make eye contact, and shake hands to begin a visit on good terms. Along these lines, clinicians should then avoid sitting behind a computer screen for most of the encounter. Managing time to allow adequate time for patients to voice concerns, sitting at the patient's level, and trying to make patients feel comfortable in exam rooms can be important expressions of a clinician's commitment to being present with the patient and setting a positive tone during encounters.^{45,46} Crucially, these small actions need not add substantial quantities of time to the encounter, but they enhance quality.

Ethics and Time

A number of articles have focused on the tension that might exist between SDM and limited clinician time.^{5,7,8,9,10} As we have suggested, focusing on ways to improve the quality of time clinicians spend with patients can help resolve this tension. Emphasizing quality becomes easier after acknowledging the ethical components of time, a subject that has received little attention in the literature.^{47,48,49} When time is narrowly conceived in terms of quantity, it diminishes potential solutions to what appears to be an intractable problem. Being attuned to the ethical significance of time, however, directs attention to one's duty to enhance the quality of time. Time is not just a barrier to obtaining histories and physicals, health record charting, or educational opportunities; it is a common obstruction to fulfilling basic ethical obligations to facilitate SDM.

Both time quantity and quality are necessary to **build therapeutic capacity** in patient-clinician relationships and to maintain focus on the virtues of compassion, trustworthiness, integrity, discernment, and conscientiousness.⁵⁰ Time is crucial to clinicians' establishing proper rapport with patients, fostering trust, being a patient advocate, and getting to know a patient. Cultivating strong patient-clinician relationships improves outcomes,^{18,51} patient satisfaction,²⁵ and expresses a clinician's moral character.⁵⁰ It is in this type of relationship that SDM can be accomplished.

Conclusion

Clinicians need to value SDM and should strive to practice it even when time is limited—a goal we believe is achievable if they become more aware of how they perceive and use time. When the debate over time is framed solely as a quantitative issue, clinicians lose sight of time's ethical significance and their obligation to maximize time quality to address time shortages. They should focus on restructuring how they navigate visits instead of defaulting to trimming minutes from encounters. Understandably, this approach may not always be feasible, but clinicians simply becoming more cognizant of how they spend their time may pay dividends for patients and clinicians alike.

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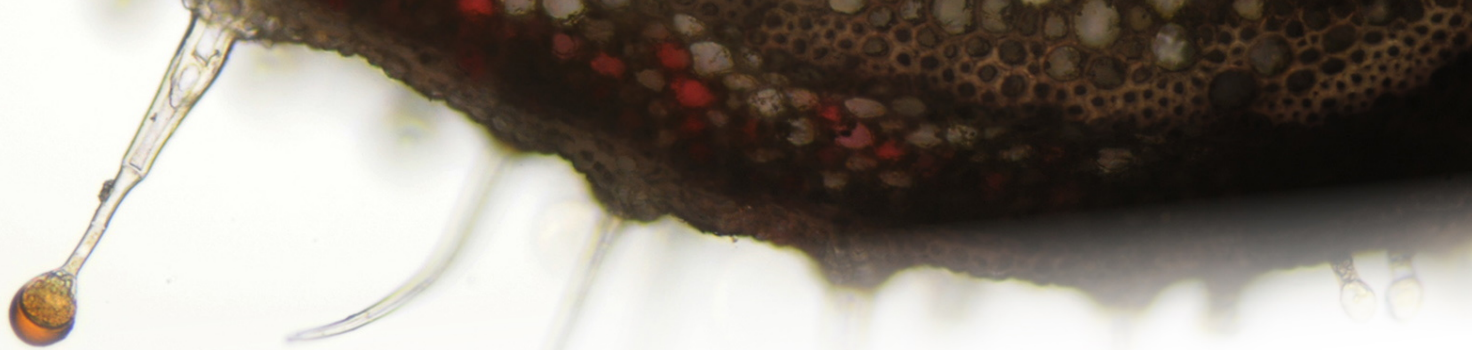
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HISTORY OF MEDICINE

What Does the Evolution From Informed Consent to Shared Decision Making Teach Us About Authority in Health Care?

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Abstract

This article examines the legal doctrine and ethical norm of informed consent and its deficiencies, particularly its concentration on physician disclosure of information rather than on patient understanding, which led to the development of shared decision making as a way to enhance informed consent. As a vague and imprecise rubric, shared decision making encompasses several different approaches. Narrower approaches presuppose an individualistic account of autonomy, while broader approaches view autonomy as relational and hold that clinician-patient relationships grounded in good communication can assist decision making and foster autonomous choices. Shared decision making faces conceptual, normative, and practical challenges, but, with its goal of respecting, protecting, and promoting patients' autonomous choices, it represents an important cultural change in medicine.

Informed Consent

Valid consent can authorize another person to do something that would otherwise be impermissible. A clear example in the medical context is a surgical intervention: cutting on a person's body requires that person's consent. The requirement to obtain patients' consent before medical interventions was expanded in the last half of the 20th century through judicial decisions, including *Salgo v Leland Stanford Jr University Board of Trustees* (1957), which added a crucial adjective to create the new term *informed consent*.¹ These decisions addressed cases in which patients alleged that they would not have consented to certain interventions (such as translumbar aortography or laminectomy) had they been informed about the risks involved.^{2,3}

Early on, informed consent as a legal doctrine focused almost exclusively on the physician's disclosure of information rather than on the patient's understanding of that information.^{2,3} The standard of information disclosure in many jurisdictions is still what prudent physicians consider normative practice (the professional practice standard) rather than what reasonable persons would want to receive (the reasonable person standard, a later judicial standard).^{2,3,4}

Analysts such as Alexander Capron have identified several functions of informed consent⁵:

- Promotion of individual autonomy
- Protection of patients and subjects
- Avoidance of fraud and duress
- Encouragement of self-scrutiny by medical professionals
- Promotion of rational decisions
- Involvement of the public (in promoting autonomy as a general social value and in controlling biomedical research)

While recognizing such an array of possible functions, many ethical and legal justifications for the requirement of informed consent are based primarily on the first function, respect for personal autonomy or self-determination.^{3,4,6} Others, such as Dickert et al, appeal to several of these functions to justify informed consent rules and practices in either clinical care or clinical research.⁷

By the last quarter of the 20th century, widespread reservations had emerged about informed consent as a legal doctrine—also stated as an ethical norm—and practice, particularly whether it actually respects, protects, and promotes patient autonomy.² Critics attacked the virtually exclusive attention to health professionals' duty to disclose information, particularly as interpreted through a professional standard rather than a reasonable person standard or the subjective preferences of particular patients. The duty to disclose was mainly discharged through the consent form, with less attention to both the *process* of consent and the patient's understanding of risks and benefits of and alternatives to a particular test or treatment.^{8,9} Moreover, the physician's involvement in the consent process appeared to be limited to serving as a conduit for the neutral disclosure of information, with little or no guidance about how the patient or subject might understand, process, and respond to the disclosed information.¹⁰ In practice, responsibility for "consenting" patients (an unfortunate and misleading verbal construction of this crucial activity) often devolved on residents and became routinized as one more preprocedure checklist item. In the end, patients could feel neglected, even abandoned, as they alone assumed and exercised the burden of decision making, as in Marcia Lynch's poem "Peau d'Orange," in which a patient with terminal breast cancer addresses her doctor:

We barter the difference
between black and gray.
"Surgery, radiation or
death," you say and leave
the decision to me.¹¹

Shared Decision Making

These and other perceived deficiencies of informed consent led to the development of what has come to be called shared decision making (SDM). In 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued an influential report, *Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*.¹² This report viewed informed consent as "active, shared decision making" and is widely considered to be the documentary origin of SDM in

health care: “Ethically valid consent is a process of shared decision making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments.”¹² This conception of SDM builds mainly on 2 ethical values manifest in the functions of informed consent: the patient’s self-determination and personal well-being.

The Silent World of Doctor and Patient, published in 1984 by lawyer-psychiatrist Jay Katz, on whose work the commission had drawn, called for an end to “the history of silence with respect to patient participation.”¹³ Instead, Katz proposed ideal medical relationships based on “sharing the burdens of decision” and “joint undertaking.”¹³ He focused more on “the entire give-and-take process than on whether a particular disclosure has or has not been made.”¹³

SDM, which as a practice continues to evolve, has since been praised as “the pinnacle of patient-centered care.”¹⁴ And, over many years, it has emerged as an ideal of clinician-patient relationships for a number of health care and professional organizations in the United States and Europe.^{15,16} SDM is often described as a middle way between a paternalistic approach (the physician knows best) and an autonomy-based approach (the patient knows best).¹⁶ It recognizes both physician beneficence and patient authority and respects, protects, and supports patients’ autonomous choices.

Narrow and Broad SDM

Nevertheless, to this day SDM remains vague and imprecise because it encompasses so many different approaches.¹⁶ One important distinction is between narrow and broad models of SDM. As Vikki Entwistle and Ian Watt draw this distinction, narrow models focus mainly on information exchange in which health professionals provide research-based information about options and their risks and benefits and patients indicate their value-based preferences and choose among options.¹⁷ These models aim to protect patients from health care professionals’ undue influence—hence their emphasis on the neutrality of the information provided. These narrow conceptions presuppose a highly individualistic view of personal autonomy; regard patient preferences as clear, settled, firm, and enduring; and hold that these preferences can reliably be used in decision making. Such models have particular importance in the acute care context.¹⁷

Drawing on Entwistle and Watt, with modifications and additions, we can say that broad models of SDM presuppose a less individualistic view of personal autonomy that recognizes positive and negative social impacts on self-determination.¹⁷ These models appreciate that patient preferences are often unclear, unsettled, changing, variable, and context and relationship dependent. They also acknowledge that health professionals might need to **support patients’ discernment**, criticism, and deployment of their own values and preferences—for instance, through recommendations and probing questions. If the decision-making process includes a more collaborative conversation, practitioners can invite patients to explore their preferences, expectations, and rationales. The 2 parties can then partner in determining the patient’s best choices in the circumstances.

Broad models overlap with and can helpfully draw on *relational autonomy*, as developed by feminists and other thinkers.¹⁸ Relational autonomists emphasize that autonomous choices are generally achieved or realized over time in the context of positive and negative social relations and are more fluid and less fixed than often supposed. A relational approach opens the door to modes of patient engagement and empowerment

beyond the narrow conception of SDM as chiefly information exchange. Indeed, we find goals-of-care conversations originating in broad, relational understandings of SDM. Broad models have particular value in chronic, longitudinal, or end-of-life care, in which patients' problems are often multiple, ill defined, and dynamic, requiring their—and often their **surrogate decision makers'**— active, continuing participation.¹⁵

Both narrow and broad models aim to protect patients' personal autonomy from paternalistic medical interference. Narrow models suffer from an inadequate account of personal autonomy and thus excessively limit potentially valuable clinician involvement. By contrast, clinicians' paternalistic tendencies might be harder to constrain and control in the broad models' pursuit of patient participation, engagement, and empowerment.

Challenges for SDM

SDM faces conceptual, normative, and practical challenges. Some ethicists contend that SDM might actually threaten patient autonomy because of its vagueness and incoherence: Exactly how can clinicians and patients share a medical decision?¹⁹ Some versions of SDM favor a division of labor, with health professionals providing research-based factual information and patients adding their personal value-based preferences.^{16,17} More often, SDM is characterized as patient and physician reaching a joint decision through collaborative, conversational deliberation.^{13,20} However, this approach could fail to sufficiently emphasize the patient's basic legal and ethical rights to know and to decide. Indeed, the term *sharing* sounds too weak when the patient actually has these rights to know and decide. In response, Peter Ubel and colleagues concede that SDM could be better described as “assisted decision making,”²¹ thus bringing informed consent and SDM closer together, as they were in the report of the President's Commission.

Serious practical barriers remain for SDM. These include the fundamental power differential between doctors and patients in clinical care or research, residual paternalistic tendencies among many clinicians,²² and the fears of many patients that they will be labeled “difficult” and receive less adequate care if they participate too actively or assertively in decision making.²³ Another critical barrier is the time SDM requires, given all the demands and constraints on physicians' time and limits on reimbursement for time spent conferring with patients.²⁴ Alston and colleagues identify still other obstacles, including uneven training of clinicians in the communicative skills needed for SDM, insufficient access to excellent decision aids, conflicting agendas in clinical encounters, and uncertainty about whether and how far to commit to SDM in clinical contexts.²⁰ For these and other reasons, Alston and colleagues stress that “the promise of SDM remains elusive.”²⁰

Conclusions

SDM's widely recognized goals are “to make decisions in a manner consistent with the patient's wishes”¹⁶ and “to respect patients as individuals and to deliver care consistent with their values and preferences.”²⁵ In an open communication process, patients might well choose their own mode of participating in SDM. At a minimum, they should be able to determine how much they want to know and what decisions to participate in. Nevertheless, any SDM activity will likely require the clinician to commit time and mindful attention to conversation that can elicit and explore the patient's values and preferences.

The word *from* in the title of this essay—“From Informed Consent to Shared Decision Making”—does not imply moving beyond informed consent to a totally different conceptual and procedural model. Instead, if conceived and practiced as “assisted decision making,”²¹ SDM as best practice actually validates, augments, and enriches the process of informed consent by emphasizing patients’ understanding and prioritizing of different medical interventions in light of their own values and lived experiences. Beyond improving informed consent, SDM can contribute to relationship building between health professionals and their patients through patient participation, engagement, and empowerment as well as through clinician presence, patient-specific focus, and improved communication. In addition to meeting ethical requirements, such constructive interactions of patients with their health professionals could actually improve outcomes and increase patients’ understanding, trust, and adherence to treatment plans.

In response to challenges to SDM, Ubel and colleagues contend that it is ethically dangerous to use SDM’s conceptual, normative, and practical problems to undermine its legitimacy.²¹ Since a primary goal of SDM is to respect, protect, and promote patient autonomy, “it would do more harm than good to question the legitimacy of the term ‘shared decision making’ at this point,” when SDM is finally being accepted “as part of standard medical practice.”²¹ Even if SDM is not the best term or clearest descriptor for the process by which clinicians and patients work together to arrive at the patient’s decisions, SDM does represent a significant evolution in medical culture such that patient autonomy is key and clinicians are expected to consider and, within appropriate limits, abide by their patients’ preferences.

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ART OF MEDICINE

What Cy Twombly's Art Can Teach Us About Patients' Stories

Jay Baruch, MD, Stacey Springs, PhD, Alexandra Poterack, and Sarah Ganz Blythe, PhD

Abstract

Some patients' stories can be hard to tell and hard to listen to, especially in pressured, time-pinched clinical environments. This difficulty, however, doesn't absolve clinicians from a duty to try to understand patients' stories, interpret their meanings, and respond with care. Such efforts require clinical creativity, full engagement, and the recognition that emotions and personal feelings leak into the space between storyteller and story listener. Art objects are complex bodies of information that can challenge clinicians and trainees to become more comfortable with messy narratives as well as with ethical and aesthetic ambiguity. By slowing down and observing art, trainees can reflect on how clinicians make sense of stories that contain information that appears random and lacks coherence—and, more importantly, how clinicians draw on these stories to respond to patients' needs.

Figure. *Untitled*, 1968, by Cy Twombly



© Cy Twombly Foundation.

Media

Oil and crayon on canvas.

Before You Can Help Patients, You Have to Understand Their Stories

Almost every patient encounter begins with a story. Some can be hard to tell and hard to listen to, especially in pressured, time-pinched clinical environments. That something is difficult, however, doesn't absolve clinicians from their duty to try to understand patients' stories, interpret their meanings, and respond with care. Clinicians' ability to respond in ways that are true to a patient's story and that are clinically astute and empathic necessitates assigning proper weight to what is said, how it was said, and what might have been left out, concealed, or disguised. Critical creativity—the ability to tolerate stories' ambiguities and uncertainties—is vital when exploring the space between **storytellers and story listeners**, especially in clinical settings. Clinicians' emotions and feelings can sneak into these spaces where meaning is created, influencing how fragments of information are assembled into recognizable and understandable narratives.

Untitled

The American painter Cy Twombly's *Untitled*, which is part of the collection at the Rhode Island School of Design (RISD) Museum, offers students, trainees, and clinicians the opportunity to become comfortable with discomfort. By slowing down their thinking, they

can reflect in more granular detail upon the process whereby clinicians try to make sense of stories from what appears to be random and nonlinear information.

Students, trainees, and clinicians of various types have sat before this work of art as part of a series of collaborations between medical educators at Brown Emergency Medicine, the Warren Alpert Medical School of Brown University, and RISD Museum educators. Medical school-museum partnerships have become more common in health care education and serve many different aims, including fostering empathy and **improving observation skills**.^{1,2,3} The partnership between faculty at Brown University (with which the first and second authors are affiliated) and the museum at the RISD (with which the third and fourth authors are affiliated), which dates back to 2011, has focused on using museum objects as complex bodies of information to provoke students to think about how they think.^{4,5} For this discussion, we'll focus on how this art object pushes clinicians to interrogate their reactions and responsibilities to challenging patient stories.

Entering the Story in the Middle

It's hard to fully understand one another. People have public faces and secret, inaccessible lives. Knowing people in all their complexity and contradictions is serious and often difficult work.

Telling stories involves choices. Deciding what information to include and leave out can be a daunting task, especially for patients whose medical experiences are complicated and difficult to put into words or layered with a hornet's nest of socioeconomic factors and mental health issues. Where patients begin their narrative can be a difficult choice that listeners accept without questioning.

At the RISD Museum, clinicians, students, and trainees sit before *Untitled* for a few minutes of quiet looking. They're then asked what they see, what stands out for them. The Twombly painting doesn't offer any soft landing spots for the eyes of viewers when they encounter it for the first time. One person's starting point might be very different from someone else's. Typically, students search for something recognizable to latch onto, a decision that involves quick and premature judgments. Are these butterflies flying off the center of the canvas? Maybe they're hearts? Ambiguity and uncertainty breed discomfort. Reaching for labels and names is an unconscious reflex to quiet the unease. But students soon realize this and begin to understand that the inquiry demands that they operate out of that unease.

Cia Panicker (*née* Mathew), a former medical student at the Warren Alpert Medical School of Brown University, wrote that she "stared deeper into the chalkboard scrawls" and "found myself getting lost and frustrated at the same time. There was so much not said with this piece. There was so much left unclear. It was a mess. Twombly lives in the tension between knowing and not knowing, between communication and lack of communication. His blackboard scribbles irritated me, and now I believe that is exactly what he intended to do. He forced me [to] sit in the unknown."⁶

Narrow Your Focus to Get a Bigger Picture

After allowing a few minutes of quiet looking, we ask students to select a small area of this Twombly painting. They're instructed to find a particular line or mark and make a sketch on paper, following the artist's hand as they sketch. In this way, they get to play with the idea of *positive space* and *negative space*. Positive space is an area that has

marks or information. We ask them how it feels to draw the lines, and we ask them to make a list of words to describe the experience of drawing them. They discover that creating childish-appearing and carefree lines is much harder than it appears. They also become aware of details that had previously escaped their notice. Ultimately, this exercise offers an alternative way of knowing that expands and deepens their curiosity regarding what the painting might be communicating.

Students are then asked to select an area they perceive as negative space—space around the marks, supposedly without information. Negative space, they quickly realize, is relational, in reference to something. By trying to represent the texture and the quality of the negative space, they're forced to look more closely. They quickly notice shading or hashmarks or squiggly lines—rich visual information in spaces that they first thought were devoid of content. The group then reflects upon this experience, and we connect what they've learned to the task of working with words and language. We in effect ask, “When you're listening to stories, are you sensitive to the gaps, mindful of what was unsaid—perhaps even unsayable?”

We ask students to think about a difficult conversation and to sketch a line or a series of lines that represent something important that they said or that was said to them. Consider this the positive space. What was said and why? How did the other person respond? Now depict that interaction on the page. The lines don't need to be artistic or even straight.

The negative spaces in this interaction are addressed next. How are those represented on the page? What was communicated when they thought nothing was happening? By representing narrative experience in this manner, they begin to see how marks and their absence can communicate ideas. They become sensitive to the textures of human interaction: the tone of voice, the weight of silence, the emotional tenor, the struggle for words, the language of the body. And where were these elements vital to communication located? They were frequently drawn in the area identified as a negative space.

Many students are self-conscious about their drawing ability. We insist that artistic quality isn't important. The focus of this exercise is to capture their thinking process on the page and to examine closely **how stories are constructed** and understood in medicine and in their lives. They soon discover that where we set our eyes and what we value as relevant information are decisions we make even before we think we're making decisions.⁷

Through sessions such as this one, physicians in training have the opportunity to play with nonlinear and even illogical information. They become aware of what information they hold onto and why. And they notice the impact of their personal feelings on the selection process. They also learn how to communicate from inside a complicated experience.

Negative Spaces and the Stories We Don't Hear—Medically Unexplained Symptoms

The writer and art critic John Berger said, “I know of no other visual Western artist who has created an oeuvre that visualizes with living colours the silent space that exists between and around words. Cy Twombly is the painterly master of verbal silence!”⁸

Consider this short hypothetical dialogue between a physician and patient: “We'll be discharging you from the hospital, soon,” says the doctor. “You're going home.” “Oh,

that's ... wonderful," the elderly patient says. She pauses. "My husband died last month." "I'm so sorry to hear that," the physician says, holding her hand. "Your tests were all negative. You must be excited to sleep in your own bed."

Patients might cue their real concerns indirectly. In this case, the woman's grief is compounded by the thought of sleeping alone in her bed and not having someone at home to care for her. One study showed that physicians often respond by neglecting these cues or by not following up and exploring these concerns further.⁹ They were more likely to respond to the problem underlying the emotion when the problem involved logistical or biomedical issues as opposed to grief.⁹ But these cues are often quiet cries for help. Surprisingly, in one study, visits with missed opportunities to address patients' clues—direct or indirect comments about their psychological or social concerns—were longer than those when those clues were picked up.¹⁰ In another study, physicians were courteous to patients even while ignoring their more pressing existential concerns. The authors labeled this phenomenon "a moral offense."¹¹

Silence

Stories are rich with silences and gaps. Communication requires attention to what's said and sensitivity to what's not said. Perceived negative spaces are often harbors of vital and tender details. The portrait of a life in crisis might look not like a portrait but like wild and disconnected brushstrokes.

The quiet, curated museum can destabilize clinicians in training and serve as safe spaces for them to work within the uncertainty and instability of clinical practice. The moral duty to care for patients with dignity and compassion begins with caring for their story. There's a difference between thinking *about* stories and thinking *with* stories.¹² Clinicians have an ethical responsibility to sit with these stories, especially if to do so feels like grasping at the ungraspable. When patients entrust clinicians with their stories, they're opening a window onto their struggles and complicated lives. By devaluing or ignoring what's chaotic and confusing in a patient's story, we devalue the vulnerable teller of the story. Not all patients expect an answer, but they all deserve a meaningful response. This can only happen when physicians possess the skills, the courage, and the creativity to explore negative space with just as much consideration and rigor as they do marks.

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ART OF MEDICINE

Modernizing Sir Luke Fildes' *The Doctor*

John Brewer Eberly, Jr, MD, MA

Abstract

Sir Luke Fildes' *The Doctor*, exhibited in 1891, is a classic work, celebrated for presenting a physician's posture, presence, and concentration before a patient. This reimagination of Fildes' work responds to modern demands on the patient-clinician relationship while suggesting the persistence of this relationship's sanctity.

Figure. Sir Luke Fildes, *the (Modern) Doctor*



Media

Gold leaf and soft carbon on medium paper; digital composite matte and diptych frame.

Caption

Sir Luke Fildes' *The Doctor* is owned by Tate Britain and was first exhibited in 1891.¹ A classic portrayal of a physicianship, it is celebrated for presenting a physician's attentive posture and presence before a patient.

Today, physicians navigate new challenges in patient-clinician relationships. In this diptych reimagination of Fildes' physician, the physician leans over an empty computer screen in the left panel, suggesting contemporary frustrations of burnout and bureaucracy in modern practice. The patient in the right panel is framed separately,

divided from the physician by a wide gap. Yet they remain facing each other. Indeed, despite burdens on practitioners of modern medicine, some qualities remain the same: patient and physician are backlit by gold leaf, a traditional symbol of sanctity among many artists and iconographers, suggesting the sacred nature of patient-physician relationships and of healing as an endeavor.

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ART OF MEDICINE

Hold Me

Shengxun Lin

Abstract

In 2010, artist Shengxun Lin created *Hold Me*, a cast resin replica of her own hand as a comfort object and stress reliever. This work continues that practical design theme with a focus on how use and comfort augment aesthetics.

Figure. *Hold Me*



Media

Resin, green acrylic, clear glaze, cotton webbing.

All of us are aware of how **holding hands** with another human being can create an instant intimacy, build deeper connection, and decrease levels of stress. An instinctual reaction is a feeling of comfort when someone holds our hand, since it can impart a sense of contentment and security. Inspiration for this artwork came from observing my cousin's newborn baby, who used his small hand to reach for and latch onto his

mother's finger. Perhaps because our hands are symmetrical, we never try to comfort ourselves by holding our own hands. This sculpture, *Hold Me*, creates opportunity for one to hold one's own hand and explores how grasp of one's own hand might bring one closer to oneself, physically and emotionally. A person can hold it when feeling lonely or insecure.¹

Using my own hand, the **mold for this sculpture** was cast in resin, which I chose for its density. The weight and temperature of the resin material in this sculpture is similar to that of a real hand (it's not as heavy or cold as metal). The cotton webbing handle expresses a portable design, useful as a handle or to comfort oneself, like a stress ball. Because I find green a calming and supportive color, I used a green acrylic and clear glaze, but any color could be used. *Hold Me* is a comfort tool: through simply grasping it, a user can feel more content and safer. This sculpture also creates opportunities for people to touch and spend more time with themselves. Our bodies, from our nerves to our brains, respond positively to touch and crave it from the time we're born. One study showed that hand-holding effectively reduced blood pressure, heart rate, and anxiety in cataract surgery patients.² If holding hands is beneficial during a traumatizing surgery, surely it is beneficial in daily life. Whether due to instinct, comfort, intimacy, or love, touch brings us closer to each other.

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Shengxun Lin is a senior product design student who works with materials such as wood, metal, plastics, paper, fabric, and leather. Her interests include drawing on technological and traditional designs to inject more human-centered experiences and functionalities into our daily lives.

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This sculpture was displayed in the exhibition, "BODIES: SAIC Intro to Designed Objects," held at the International Museum of Surgical Science, November 15, 2019 through February 16, 2020.

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ART OF MEDICINE

Salvation in a Time of Plague

Ginia Sweeney, MA

Abstract

Health workers offer their skills and care to COVID-19 pandemic patients, just as St Roch offered healing to those stricken by bubonic plague during the Renaissance. This article interprets 3 works of art in light of Roch's story of illness and recovery and applies key insights of ethical, artistic, and clinical relevance to the COVID-19 pandemic.

Pandemic Pilgrim

Outbreaks of bubonic plague devastated Venice, Italy, throughout the Renaissance. Beginning in the 15th century, a devotional cult sprang up around the figure of St Roch, locally known as San Rocco, who offered solace to those unsettled by the immense amount of death that surrounded them. One early biography documents the reliable success of Roch's deeds: "Those suffering from the plague, fleeing to the protection of Roch, will escape that most violent contagion."¹ Writers, theologians, and public health officials assumed plague had supernatural origins, acting as a punishment from God against a sinful population.² In the absence of effective treatment or disease prevention strategies, Venetians turned to these specialized plague saints, hoping desperately that they would intervene on the city's behalf. As successive epidemics ravaged the city, Venice became a center of the cult of St Roch.

St Roch's life was first recorded visually, as a figure in several mid-15th century altarpieces, and later in writing, in 2 hagiographic novels published in the 15th century.¹ Briefly, the novels relate his life: born to noble French parents in the mid-1300s, around the time of the **Black Death**, Roch embarked on a pilgrimage to Rome as a young man. Setting aside his privileged origins, donning a hooded robe and carrying a sack and a staff, Roch traveled on foot and stopped short of his destination. He arrived instead in the central Italian town of Acquapendente, which was overcome by pestilence. Roch rushed to the hospital, seeking entry, to the incredulity of the hospital director. Once inside, Roch blessed plague patients, releasing them from the torments of illness.

Roch repeated these acts of miraculous healing, spending ensuing years traveling to cities ravaged by plague, entering "houses of the poor and hospitals" to free the afflicted from disease.¹ Perhaps inevitably, Roch became infected himself and immediately took refuge in a forest to avoid becoming a vector of further contagion in the city. Although he expected to perish, a fresh-water spring appeared next to him and a dog brought him bread each day, sustaining him until he recovered.

Representations of Roch

Roch cuts a distinctive figure. Clad in pilgrim's garb, he was often depicted drawing attention to a plague bubo, a painful swelling caused by the disease, on his thigh. (The bubo would have actually appeared in an affected person's groin, but artists generally depicted it on a thigh.) This symptom's representation forges empathetic connection with viewers, reminding them that Roch suffered the disease from which he sought to release others. These images proliferated in Italy during the mid-1400s. For example, in a polyptych by Antonio Vivarini, dated to about 1464 (see Figure 1), Roch appears in the lower right panel, accompanied by the faithful dog who helped nourish him in the forest.³

Figure 1. *Polittico coi ss Antonio Abate, Sebastiano, Cristoforo, Venanzio e Rocco*, by Antonio Vivarini (Italian, 1440-1480)



Vatican City: Pinacoteca Vaticana. Photo by Sailko. Licensed under [Creative Commons Attribution ShareAlike 3.0 Unported](https://creativecommons.org/licenses/by-sa/3.0/).

This representation of Roch continues in an engraving (see Figure 2) dating to 1530 by an anonymous Italian artist, known as the Master of the Die, and is in the collection of the Art Institute of Chicago. Roch is shown bearded, in humble pilgrim's robes and sandals, with his thigh pressed forward, exposing a darkened patch that likely indicates a bubo. At his foot, the friendly dog carries bread.

Figure 2. *St Roch*, c 1532, by Master of the Die (Italian, active c 1530-1560) after Raffaello Sanzio, called Raphael (Italian, 1483-1520). The Art Institute of Chicago®. This information, which is available on the object page for each work, is also made available under Creative Commons Zero (CC0).



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In response to another outbreak of plague in Venice in 1478, the Scuola Grande di San Rocco, a confraternity through which non-noble citizens could involve themselves in city

governance, was established.⁴ Members committed themselves to following the charitable example set by San Rocco to serve the poor and sick people throughout the city⁵ and help eradicate the plague. The following century, the Scuola commissioned a narrative cycle of paintings by Jacopo Tintoretto depicting the life of St Roch, which remain in their original location in the Chiesa di San Rocco (Church of St Roch). In *St Roch Ministering to Plague Victims* (see Figure 3), Tintoretto represented the saint in contemporary Venice, aboard a lazaretto, a ship on which plague sufferers were quarantined. The artist vividly conveyed the agony caused by the disease through the hordes of sufferers who wince and clutch at their plague-stricken bodies.

Figure 3. *St Roch Ministering to Plague Victims*, by Jacopo Tintoretto (Italian, 1518-1594)



Venice, Italy: Chiesa di San Rocco.

Roch, at the center of the painting, with his back to the viewer and his face set off by a glowing halo, lays his hands on the bare chest of a sick man. The highly emotional scene inspires hope, implying that Roch could bring his miraculous healing to Venice as he had done, according to legend, in other Italian cities.

Pilgrims Present

Episodes of bubonic plague during the Renaissance resemble the **COVID-19 crisis**. In both cases, the diseases had enormous economic consequences, leaving many fortunate enough to remain healthy stripped of employment. **Large gatherings** of in-person worshipers were then, as now, canceled, a move that was protested by some clergy.⁵ Psychologically, plague and COVID-19 have caused uncertainty and dread, particularly among those stricken and their loved ones.

St Roch offered a balm against this existential anxiety; praying to his image was a tangible action taken by many in the face of horror and can still be done by the faithful today. St Roch's story, too, visually and narratively expresses **health care workers' courage** in risking their own safety, isolating themselves from family to tend to COVID-19 patients. Like many clinicians, St Roch sacrificed his own well-being for the health of others, offering hope when it's in short supply.

As Megan O’Grady recently noted in the *New York Times*,⁶ we don’t yet know which works of art will represent our trials during the pandemic of 2020. But just as artworks, including those of St Roch, play key roles in our memorialization of the bubonic plague, its dead, and its saints, so will art likely shape humanity’s understandings of COVID-19.

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Editor's Note

Visit the Art Institute of Chicago [website](#) or contact Sam Anderson-Ramos at sramos@artic.edu to learn more about the museum’s medicine and art programming. Browse the *AMA Journal of Ethics* [Art Gallery](#) for more Art of Medicine content and for more about the journal’s partnership with the Art Institute of Chicago.

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VIEWPOINT: PEER-REVIEWED ARTICLE

Overcoming Obstacles to Shared Mental Health Decision Making

Laura Guidry-Grimes, PhD

Abstract

Shared decision making (SDM) is difficult to implement in mental health practice, but it remains an ethical ideal for motivating therapeutic capacity in patient-clinician relationships; this discrepancy warrants attention from clinical and ethical perspectives. This article explores what some clinicians see as obstacles to even attempting SDM with patients with psychiatric disabilities. In particular, this article identifies 4 such obstacles: a patient's lack of decision-making capacity, a patient's poor insight, a health care professional's therapeutic pessimism or personal dislike, and a patient's or health care professional's conflicting recovery orientations or goals of care. This article argues that each obstacle could be overcome in many cases and that health care professionals, patients, and their caregivers should remain dedicated to attempting SDM in mental health practice.

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Sharing Mental Health Decisions

The 21st century has witnessed increasing support for shared decision making (SDM) as a model of the therapeutic relationship, including in mental health contexts. Unlike paternalism and consumerism, this model encourages a patient and health care professional (HCP) to partner in identifying and appreciating facts and values relevant to good decision making, even in cases in which patients' decision-making capacity or insight might be compromised by illness or disability. SDM includes recognition of the dual expertise of the HCP and patient, bidirectional informational exchange, collaborative decision making, and establishing trust and respect; each of these are components of therapeutic alliance in patient-clinician relationships.^{1,2,3,4,5,6}

Patients with psychiatric disabilities should be encouraged to contribute to SDM processes to the extent that they are able to do so. The Institute of Medicine and the Substance Abuse and Mental Health Services Administration champion SDM for this patient population.^{4,5} Multiple studies and surveys indicate that SDM is feasible and can

be productive in psychiatric treatment.^{3,6,7,8,9} Furthermore, SDM can help motivate self-determination, a key value in the user/survivor movement.¹⁰

In practice, however, SDM can be difficult to implement.^{2,3,6,11} In a survey published in 2009 that is notable for its detailed exploration of psychiatrists' judgments about SDM, 51% of 352 psychiatrists claimed that they implemented SDM; 5% reported that they most frequently aimed to implement whatever treatment the patient preferred; and a surprising 44% still preferred a paternalistic approach.¹² A subset of psychiatrists rated whether patient characteristics or decision topics would influence whether they used SDM with **patients with schizophrenia**. When patients demonstrated disturbance of thought, depression, mania, shallow affect, or poor insight, the ratings of the surveyed psychiatrists indicated that they would be less inclined to pursue SDM with patients.¹² And whereas psychosocial decisions (such as discharge options and psychoeducation) were considered prime topics for SDM, the surveyed psychiatrists viewed most medical and legal decisions (such as hospitalization options, prescriptions, and diagnostic procedures) as unacceptable topics for patient participation.¹² Many medical and legal decisions, however, are decisions that patients may reasonably care about most. (Interestingly, this study, as with others on this topic, focused on psychiatrists' views of taking a participatory approach with patients without considering how their attitudes might shift if surrogates and caregivers were included in the decision-making process.) The survey provides evidence that clinicians tend to implement SDM when doing so is uncomplicated. Patients who want to participate in SDM and who do not dispute their diagnosis, do not reject **relevant clinical facts** about their diagnosis or treatment, and do not experience negative emotional symptoms are more likely to be invited by clinicians to share in decision making about their care.

An ethical complexity worthy of exploration in the rest of this article, however, is that HCPs might hastily abandon their ethical commitment to SDM when patients' ability to participate in SDM could be undermined by their illness. This lack of commitment to SDM has important consequences for the patient-clinician relationship: what ethical commitment to decision sharing means is that clinicians trust in their patients' *worldview* and value their patients' *experiences*, both of which clinicians are obliged to support in order to nurture therapeutic capacity in their relationships with patients. Obstacles to trusting the worldview or valuing the experiences of patients with a psychiatric disability are numerous, however. This article considers 4 of the most important ones: patients' lack of decision-making capacity, patients' lack of or poor insight into their illness, clinicians' pessimism about treatment, and conflicting visions of a path to recovery.

Incapacity

One might think that SDM can only be achieved when all stakeholders have decision-making capacity. To have capacity to make a particular health decision at a particular point in time, a patient needs to communicate a choice and demonstrate not only sufficient understanding of and reasoning about treatment choices, but also appreciation of the likely consequences of a choice.¹³ Since psychiatric disability can diminish a patient's capacity to make health decisions, especially high-stakes decisions, it might seem that an incapacitated patient cannot meaningfully participate in SDM.

Nevertheless, many patients with psychiatric disabilities **retain capacity** for all or most decisions.¹⁴ Thus, HCPs should be careful not to assume that patients with schizophrenia, for example, cannot make their own decisions on the basis of the diagnosis alone.¹⁴ Additionally, a patient's capacity can fluctuate, so even when a

patient has difficulty contributing to decision sharing during, say, an acute exacerbation of an illness, that patient's capacity to participate in decisions about her care should be reevaluated.¹⁵ While a patient has capacity, an HCP can facilitate current and future SDM by recording the patient's preferences, values, and health experiences (eg, hospitalizations and treatments). A psychiatric advance directive or other form of documentation can help patients clarify their values and preferred care plan during acute episodes.^{4,5,16}

Even when a patient lacks capacity to make a specific health decision, the patient perspective is still worthy of regard and should be considered. Patients lacking capacity can still have enduring interests and values, and their input might provide critical information about, say, how a particular medication makes them feel or how difficult or easy it is to adhere to specific treatment demands. Successful SDM can also incorporate input from family members, friends, caregivers, or others with a long-standing relationship with the patient who can clarify the patient's particular interests and who can assist the patient in communicating preferences.

Poor Insight

Insight refers to patients' self-understanding of their condition. Patients' insight tends to be assessed when they reject a diagnosis or treatment. If an HCP believes a patient lacks or has poor insight, it might seem pointless to try to share treatment decisions with that patient. In fact, numerous studies have found that HCPs consider lack of or poor insight a substantial barrier to SDM.^{11,17}

I have argued elsewhere that insight is conceptually ambiguous, that insight assessments are made without standardized bedside tools, and that such assessments carry too much weight in clinical decision making.¹⁸ But even when a patient lacks insight, as Marga Reimer points out, some patients can nonetheless identify interests that could be served with a treatment plan.¹⁹ For example, patients might disagree that they have any kind of thought disorder but still want help for calming their nerves.¹⁹ In a 2016 study of patients with psychiatric disorders, motivation and perception of treatment benefit predicted treatment adherence significantly better than insight.²⁰ This finding suggests that a patient's lack of or poor insight should not predispose HCPs to abandon decision sharing with a patient.

Clinicians' Therapeutic Pessimism

Numerous studies over the years have shown that HCPs tend to have negative attitudes toward patients with certain diagnoses, especially personality disorders, and these attitudes manifest as doubts about treatment efficacy (therapeutic pessimism) and strong personal dislike.²¹ SDM requires empathic communication, especially from the clinician; creative problem solving; and close attention to one another's perspectives. SDM can thus seem out of reach when the therapeutic relationship is tainted with intense negative attitudes.

Part of the professional obligation to communicate empathically with patients is to be self-aware, particularly about **negative countertransference** that can undermine therapeutic capacity in one's relationship with a patient. Clinicians are further obligated to prevent, or at least not to exacerbate, stigma suffered by patients with psychiatric disabilities. Resources promoting anti-stigma education²¹ could help HCPs remain vigilant about their negative countertransference reactions, how these reactions influence their ability to take care of patients, and ways of cultivating more appropriate clinical dispositions, including empathy. Jodi Halpern, for example, argues that engaged

curiosity is necessary for developing and expressing clinical empathy. With engaged curiosity, “[T]he basic stance is one in which the physician recognizes that he or she does not fully understand and has more to learn about the patient’s situated experience.”²² Halpern also emphasizes that conflict does not necessarily mean empathy has failed and that “simply making the effort to understand the other person’s perspectives plays a helpful role in conflict resolution.”²² As long as an HCP does not give in to hopelessness or distrust, empathic engagement remains possible, which means that SDM might be a possible and a reliable way to nourish therapeutic capacity in one’s relationship with a patient.

Conflicting Visions of a Path to Recovery

In SDM, an HCP and a patient should forge an agreement about the therapeutic goals of their work together. Therapeutic goals reflect values and priorities in decisions about what counts as a benefits, harms, or acceptable trade-offs. HCPs tend to have a clinical orientation to what “recovery” looks like, so, for HCPs, getting better would likely include symptom alleviation and restoration of a patient’s ability to pursue activities of daily living independently.²³ But a patient might prioritize self-esteem, hopefulness, or other conceptions of what it means to live well.^{23,24,25} Such differences in vision are important because SDM can come to a halt when HCPs and patients disagree on what counts as getting better. If a medication, for example, is perceived by a patient as threatening their personal goals and perceived by a clinician as valuable because it minimizes symptoms, the therapeutic capacity of the patient-clinician relationship will be stymied by distrust and incommensurable visions of how to proceed and of what’s worth doing.

Asking patients what getting better means to them should be a first step in SDM; this question elicits patients’ values and overall perspectives on their condition and treatments. If at all possible, an HCP and a patient (and perhaps a surrogate) should work together to formulate a care plan that protects what the patient finds valuable while also addressing the patient’s needs from a clinical perspective. The patient’s lived experiences will be critical for understanding which personal costs of treatment are acceptable. One example of this approach is the CommonGround program, which incorporates a peer-run decision support center, decision support software, and specialized training of HCPs to support SDM in behavioral health.²⁵ Founder Patricia Deegan, a patient advocate and clinical psychologist, has described how the HCP and patient can collaborate on recovery goals so that psychiatric medication supports what a patient finds meaningful.

Conclusion

HCPs and patients should work at identifying how each of the 4 obstacles to implementing SDM in mental health care—patients’ lack of decision making capacity, patients’ lack of or poor insight into their illness, clinicians’ pessimism about treatment, and conflicting visions of a path to recovery—undermine therapeutic capacity in their relationship and in specific decisions. Doing so can make available the benefits of SDM and can help remind all stakeholders of the persistent importance of trust, humility, and learning from one another during clinical encounters and in patient-clinician relationships.

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VIEWPOINT: PEER-REVIEWED ARTICLE

How Should Decision-Sharing Roles Be Considered in Adolescent Gender Surgeries?

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Abstract

The nascent field of gender-affirming surgery (GAS) for binary and nonbinary transgender adolescents is growing rapidly, and the optimal use of shared decision making (SDM)—including who should be involved, to what extent, and for which parts of the decision—is still evolving. Participants include the adolescent (whose goals might center on aesthetics and functionality), the surgeon (who might focus more on minimizing complications), the referring clinician (whose participation is mandated by present standards of care), and the caregiver (whose participation is required for patients below the age of consent). This article argues that effective, ethical SDM in adolescent GAS care requires a different conceptualization of roles than might be expected in other situations and should be a longitudinal experience rather than a singular event.

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Adolescent Gender Surgery Decisions

Gender affirmation is, fundamentally, the use of social, medical, and surgical processes to reify individuals' sense of themselves as a gendered being. The nascent field of **gender-affirming surgery** (GAS) is growing rapidly, particularly in its understanding of optimal techniques and outcomes. This is especially true for adolescent surgeries, as the existing literature predominantly focuses on adults,¹ which is in line with clinical practice guidelines that presently recommend gender-affirming genital surgeries be deferred until the age of majority.^{2,3} However, both the World Professional Association for Transgender Health's Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People and the Endocrine Society's clinical practice guidelines, Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons, state that chest surgery may be performed prior to the age of majority depending on the individual,^{2,3} and a number of surgeons acknowledge performing genital surgeries prior to age of majority.⁴ In addition, many individuals seek GAS shortly after reaching the age of majority, which suggests that most counseling has already occurred.

Conversations concerning patients' and clinicians' expectations for GAS are often fraught. Patients might have goals centered on aesthetics and functionality while surgeons might focus more on minimizing complications.⁵ There are also inherent power imbalances in these conversations, in part due to differences in age and training, and, in moments of conflict, patients might subordinate their needs and goals to those of the seemingly omniscient surgeon. As such, decision making about the surgical goal might be characterized less by 2 persons "sharing" than by 2 persons talking past one another. Ultimately, the patient hopes the surgeon knows what's right and the surgeon that the patient knows what's acceptable. Shared decision making (SDM) is made more complex by referring clinicians, whose participation is mandated by present standards of care, and the caregiver, whose participation is required for patients below the age of consent.^{2,3} For all these reasons, the optimal use of SDM—including who should be involved, to what extent, and for which parts of the decision—continues to evolve.

How does SDM work in a field like adolescent GAS in which everyone has very different perspectives, no one participant has all the information, and the information that parties hold might seem to conflict? We argue that effective, ethical SDM concerning adolescent GAS requires taking into account a number and variety of factors and participants. By evaluating the nuances of each participant's perspective, as well as the social context for gender-affirming care, we demonstrate the ways in which SDM for adolescent GAS is different than in other areas of adolescent health. We also make the case for regarding SDM as an ongoing, longitudinal process rather than as a single, isolated event.

Surgeons' Roles

As a new field, GAS is characterized by limited longitudinal data, rapidly evolving standards, and ongoing disputes about optimal approaches.⁶ Surgeons desire to utilize techniques that minimize morbidity and maximize patient satisfaction yet are constantly faced with new procedures, such as for transgender neophallus construction.⁷ It is even more complex to assess functional outcomes, as function is integral to patients' experiences of their gendered body, sexuality, and place in society.

The surgeon's perspective is often additionally limited by personal experience. Many surgeons are cisgender, have not experienced gender dysphoria, were raised in a world in which gender was binary, and trained at a time when GAS was used to cross from one anatomically defined end of this binary to the other.^{8,9} During SDM, the surgeon might come to the table focused entirely on how to accomplish the best possible cisgender, endosex, and heteronormative functioning of their patient's neogenitalia. Making a heterosexual binary identity the default goal of surgical transition leads surgeons to see the ideal vaginoplasty, for example, as one with depth that supports phallic penetration.¹⁰ Any deviations from the default goal might be considered compromising modifications. Correspondingly, the default goal risks devaluing the needs of patients—for example, the needs of a nonbinary patient whose goals for chest surgery include a chest flat enough to bind comfortably but one that does not mimic a male contour. Thus, defaulting to mimicry of archetypical, cisgender bodies fails to take into consideration what individual patients view as *their* ideal.

Surgeons' recommendations must be put in a broader context. Just as diversity in gender and sexual orientation is no longer pathologized by some medical organizations,^{11,12} so functional and aesthetic ideals for genital functioning must be

more clearly interrogated by policymakers and legislators.^{12,13} Additionally, in a rapidly growing field, it's impossible to completely know what future improvements are forthcoming.¹⁴ Therefore, it's important for other participants in SDM to acknowledge the limitations of surgeons' recommendations—particularly if they're favoring newer practices over old, but also if they're privileging established standards over promising advances.

Nevertheless, in SDM, surgeons must bring their expertise to the table. They understand and can communicate what any given surgery can and cannot provide, as well as its associated risks. Surgeons should not assume they know the ideal outcome for any given patient but should use their experience to determine if a patient's stated ideal is realistic—or even currently possible—and advise on how best to meet the patient's goals.

Adolescent Patients' Roles

If surgeons bring procedural expertise to SDM, adolescents bring expertise in their identities and lives. They know, better than anyone else, who they are and what it is like for them to move through the world. They have the clearest picture of their GAS goals—their ideal aesthetic and functional outcomes. They might have a more nuanced understanding of the intersections between sex, gender, and anatomy than their parents and clinicians, who often have expectations for binary identity. They might also, with access to support and online information, have an understanding of the risks and possibilities of GAS that is equal to—or better than—that of physicians they consult.

However, they are also adolescents. Their brains are not yet fully mature, and they do not have the same capacity as adults to regulate impulses and weigh risks and rewards.¹⁵ They might not have the ability to determine the accuracy of information they've accessed.¹⁶ Their understanding of their gender identity and expression, sexuality, and anatomy might still be evolving. While it is important for clinicians and caregivers to accept adolescents as experts about their own lives and to afford them as much autonomy as possible, it is also important to acknowledge that they might have difficulty understanding complex information and making appropriate decisions. The adults engaged in SDM might have certain skills that the adolescent lacks, but they are also imperfect predictors and deciders. In SDM, adolescents' ideal role is to describe the goal of their gender transition journey while the adults help them identify the best route to take.

Caregivers' Roles

For adolescents below the age of majority, caregivers play a critical role in SDM. Despite this process being fundamentally about the adolescent medically affirming their self-perception of identity, caregivers are responsible for consent and thus are expected to balance the needs of the adolescent and their own theoretically greater understanding of potential long-term consequences and contexts.¹⁷ It is their duty to simultaneously support their child's growing autonomy while recognizing any limitations to that child's ability to appropriately enact it.

Caregivers of gender diverse children have various experiences with and feelings about their child's gender transition journey.¹⁸ They might be supportive, or they might put up roadblocks.¹⁹ They might feel like reluctant passengers on a gender transition journey they feel is moving too fast, or they might be driving the child's transition to address their own insecurities and needs. Ideally, caregivers are supportive copilots in the SDM

process. Having the best interests of their child in mind, they bring knowledge of the adolescent and a mature understanding of the situation to the process of making rational decisions.¹⁸ Nevertheless, they might have personal objections (ie, religious, cultural) to gender diverse identities or fears about stigma in their child's future, which could complicate their decision making.^{18,20}

It is critical for clinicians to encourage caregivers to consider their child's best interest and to be flexible during surgical decision-making processes. In some cases, it might make more sense for an adolescent to forego GAS until adulthood than to be steered by caregivers into an inappropriate surgical decision that will need readdressing in the future. When caregivers are clearly unable to act in the best interest of the patient, alternative gender-affirming pathways might need to be explored. At other times, clinicians, caregivers, and adolescents can work together on a compromise that is not ideal for anyone but functional for all, such as when parents of transmasculine youth are willing to consent to chest reconstruction surgery but not to **gender-affirming hormone therapy** to address their child's dysphoria.

Referring Clinicians' Roles

Referring clinicians are usually the first to discuss GAS with families and patients. The Endocrine Society's clinical practice guidelines, Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons, recommend participation of clinicians providing endocrine transition therapy in the surgical readiness referral process, which might make them the first clinicians to have conversations about surgery with their patients who want it.³ Different types of referring clinicians might also serve as gatekeepers to surgeons. Patients might require a referral from the clinician who prescribes their hormones or from a primary care physician to even access a surgical consult, and the current World Professional Association for Transgender Health's Standards of Care requires mental health professionals to provide readiness letters to surgeons in order for patients to move forward through their surgical journey.^{2,3} For this reason, mental health professionals might also be the first clinicians to engage in a dialogue about surgical options, outcomes, and choices, even when these conversations are not required for referral.

Despite the role they have in helping patients access surgery, referring clinicians rarely remain involved in the decision-making process once letters have been written or referrals made, except in situations in which surgeons need to coordinate complexities of care. Referring clinicians are thus simultaneously omnipresent and absent from the SDM conversation.

Conclusion

In adolescent GAS care, SDM is not a singular event but a longitudinal experience. It starts with the patient's desire for gender affirmation and leads to interactions with caregivers and referring clinicians, even before a surgeon is identified. SDM continues through surgical consultation and into the recovery period when ongoing concerns must be addressed. For SDM to be ethical and successful, it is important to acknowledge that no one participant should shape the discussion throughout the gender transition journey. Each has their own viewpoint and expertise. The ideal SDM process is one in which everyone comes to an agreement on the goal and best path forward.

Ultimately, it is critical for clinicians to allow themselves to be humble and to acknowledge patients' understanding of their gender and its alignment with their

anatomy. It is important for caregivers and clinicians to balance respect for patients' autonomy and a realistic assessment of any limitations in patients' decision-making processes. It is also essential for patients and their caregivers to acknowledge that, while GAS can accomplish some goals, it is not the golden ticket to solving all problems related to gender affirmation. Everyone involved in SDM must realize that it is possible to make the best possible **informed decision** and still have some regret, because the current reality of GAS is that it is almost never the perfect option, even when it is the best possible one.

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LETTER TO THE EDITOR

Response to “How Should Academic Medical Centers Administer Students’ ‘Domestic Global Health’ Experiences?” Ethics and Linguistics of “Domestic Global Health” Experience

Em Rabelais, PhD, MBE, MS, MA, RN and Esmeralda Rosales, MD

Sural Shah’s “How Should Academic Medical Centers Administer Students’ ‘Domestic Global Health’ Experiences?” in this journal’s September 2019 issue draws parallels between global health experience and *domestic* global health experience. For—presumably—urban, student-run clinics, Shah presents guidelines and a sample curriculum using lessons learned from international global health experiences. We, the authors, care tremendously about the/our communities that live in the shadows of urban academic medical centers (AMCs) and therefore have a stake in how these/our communities are framed, discussed, and (mis)treated. Language choices are ethical choices. Our concerns, in the context of urban AMCs, are based on the linguistic and ethical problems of *global health* and *domestic global health* when referring to care for local, underresourced, marginalized, and oppressed communities.

Medical and other health professions students commonly seek **global health experiences** (GHEs). Which students seek these, and what are their motivations? Foremost, (primarily) white people from colonial powers are motivated by *white saviorism*: the self-serving assumption that they should be “saving” or taking care of the poor in Africa and other colonized locations.^{1,2,3} White saviorism is a prominent feature of medical mission trips, domestic or international,⁴ and has roots in **colonialism**.^{1,3} GHEs are expensive and promoted as travel opportunities to international, exoticized locations in order to promote students’ understanding of culture or *Others’* cultures, given white people’s unstated denial of white culture(s). Understanding *the Other* (whiteness in action) derives from anthropology, and an early, well-known satire of otherizing is seen in Miner’s 1956 “Body Ritual Among the Nacirema,”⁵ which shows just how dangerous the colonial gaze’s framing is. The colonial/white savior gaze is not dissimilar to contemporary medical voluntourism,^{6,7} which deemphasizes sustainability and capacity building. Even if these missteps are avoided, how does understanding *the Other* in the global context prepare students to understand *the Other* in the United States?⁸ If it is to understand culture or difference, then we’ve already failed our students by reinforcing the idea that *the Other* in the global context is a respectable *Other*, while the domestic *Other* lacks this respectability in terms of culture and difference.

What is it about local urban engagement that isn't as palatable as GHEs? Why is the exoticism of global health terminology needed to make the urban United States respectable? The answers' racism is consistent with colonialist white saviorism: *urban* becomes code for *black*, or at least *not white*. (Notably, urban bioethics focuses on density, diversity, and disparity,^{9,10,11} and thereby promotes community-engaged approaches to care and research in order to foster trust.^{12,13,14}) The health professions' collective histories of racism, class stigma, othering, knowledge valuation, and individualism exist today as oppressions expressed through **structures and policy** that are supported by whiteness and white supremacy.^{15,16,17,18,19} When do any health professions students—or, more importantly, faculty—learn our histories and our contributing roles?

In AMCs, principlism is the predominant ethical framework, yet without acknowledging its history—namely, who it was made by and for—we clinicians are left thinking that principlism consists of our best approach to difficult situations. Principlism's enshrinement by a white moral philosopher and a white Christian theologian (Beauchamp and Childress) excludes literal centuries of contributions from black, indigenous, and other people of color (BIPOC) on what is considered (un)ethical or (im)moral in any medical context.^{20,21,22,23,24} The primacy of *autonomy* embraces this country's white founding on individualism and dissociates any limitations, and thus *agency*, in "making a choice." Thus framed for ("domestic") GHEs, principlism shows its paternalism, imperialism, and colonialism.

We agree with Shah in the benefits of ethics training, although we have more questions: Does the ethics training include critical humanities and social science content taught by faculty comfortable with discussing and prepared to discuss critiques of traditional, normative (health) ethics? Do all involved have or gain competency in the structures impacting the community, be it domestic or abroad? Does this ethics training include—before, during, and after provision of care—ethics *about the ethics* of students giving care? How is the primacy of autonomy handled when, unethically, patients are not told that their care is incomplete or potentially inappropriate? Does the discussion go beyond "this is better than nothing"? Most importantly, are the ethics training and program structure created in conjunction with the community, such that the domestic GHEs' *intentions* can be actualized? If an AMC has an ongoing relationship with a community partner, is there mutually beneficial engagement, which is more than students practicing giving care and communities receiving (incomplete) care? Mutually respectful relationships are a core feature of community-engaged work. To be successful and in order to earn trust they require serious investment, on the community partner's terms, from the AMC partner with histories of power.

All patients at our AMCs, recent immigrants or not, are living within the structures and oppressions of whiteness and colonialism in the United States. The problems with domestic GHEs are not with the students or communities but the faculty. We who are faculty—and are not representative of our urban AMC neighbors—perpetuate the oppressions of whiteness through linguistic and ethical choices that devalue people living in the United States as an exoticized *Other* rather than accepting them, and many urban AMCs' BIPOC neighbors, as humans with valid needs and bodies. If our students are to benefit from student-run clinics, so must the communities. Finally, we suggest that Shah's approach to ethics and curricular administration for (domestic) GHEs needs reversal: we in the United States must work out the ethics around AMCs' student-run

clinics and sustainable community engagement *before* assuming we might have appropriately and equitably designed²⁵ approaches for use globally.¹⁴

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Em Rabelais, PhD, MBE, MA, MS, RN is an academic health ethicist and assistant professor at the University of Illinois at Chicago College of Nursing. Their scholarly focus is on decentering whiteness in bioethics and health ethics and in the biomedical and health professions research, education, and practice. Dr Rabelais' scholarship and teaching establishes an inclusive and distinct ethics that prioritizes critical resistance and identity-focused narrative ethics approaches to purposefully center patient and student narrative voices as the definers of discriminations. In doing so, this ethics requires the initiation of dismantling the transmission of learned, enacted, and centered whiteness in these settings to recreate space, practice, and education as defined by those who are demanding the change.

Esmeralda Rosales, MD attended the University of Illinois at Chicago College of Medicine and will be joining Erie/Northwestern McGaw as a family medicine resident in July 2020. As a child, Esmeralda and her family emigrated from Mexico to the United States. Her family quickly learned the hardships that immigrant families face when trying to access basic health care. Inspired by her own family's struggle to afford medical care, she is committed to fighting for equal access to health care for everyone regardless of socioeconomic or immigration status. As a physician, her long-term goal is to become a family medicine physician that is at the forefront of providing treatment, education, and preventative medical services to underserved communities.

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LETTER TO THE EDITOR

Response to “Ethics and Linguistics of ‘Domestic Global Health’ Experience”

Sural Shah, MD, MPH

In “Ethics and Linguistics of ‘Domestic Global Health’ Experience,” Em Rabelais and Esmeralda Rosales raise concerns about the colonial and paternalistic roots of “medical mission” work (within the United States or internationally) and the use of the term *domestic global health*. In “How Should Academic Medical Centers Administer Students’ ‘Domestic Global Health’ Experiences,” I review parallels between community health experiences internationally and experiences serving the underserved within the United States, often with migrant populations or in student-run clinics. I use the term *domestic global health* to highlight these parallels, as has been done in the literature elsewhere.^{1,2,3} As a primary care physician within a large urban safety-net system with a focus on immigrant children and families, I agree with the authors of this response that engagement with local underserved areas within the United States is respectable and valuable without need for reference to service elsewhere. I also agree that we, as faculty at academic medical centers (AMCs), have an obligation to understand the roots of and our role in these issues, as discussed in the paper. Ultimately, we have an obligation to critically assess how our communities can be supported by AMCs, **in partnership with the communities** themselves.

However, there is limited literature on the ethics of AMCs serving the underserved domestically and how AMCs approach teaching students to serve this population.^{4,5,6} As the authors describe, this lack of literature is highly concerning and likely reflects 2 key issues: the first is the structural roots of discrimination and disenfranchisement in our communities and country; and the second is the historical popularity of global health as a field among trainees. Clearly, we must work out ethical guidelines for how AMCs approach sustainable community engagement and partnership. Furthermore, AMCs must consider their own roles in addressing systemic inequalities and inequities.

The authors raise concerns about the development of the literature on the ethics of global health engagement, beginning with the term *global health*. I agree with the Rabelais and Rosales that experiences serving the underserved domestically would be better described using a term other than *domestic global health* to eliminate concerns about “othering.” Ethically and clinically, these experiences are ultimately **community health** experiences, regardless of if they are domestic or global. The critical appraisal of the content of and training for this engagement, including training with experts in relevant humanities and social sciences content, is clearly key for AMCs.

However, if we agree that ethical structures for community engagement domestically or globally should be rooted in our communities, there are parallels with global health, many of which are cited in this same September 2019 issue of this journal. The authors themselves highlight shared themes, including colonialism, paternalism, and racism. These parallels exist regardless of the terminology used and represent critical issues in the history of academic medicine in which AMCs must consider their role. Looking to these curricula is less about their shared “exoticism” and more about the recognition of the shared history of structural violence that AMCs have an obligation to address in designing programs and curricula.

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