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How Shared Is Shared Decision Making? Reaching the Full Potential of Patient-Clinician Collaboration in Mental Health

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Abstract: Shared decision making in mental health is a priority for stakeholders, but faces significant implementation barriers, particularly in settings intended to serve people with serious mental illnesses (SMI). As a result, current levels of shared decision making are low. We highlight these barriers and propose that a novel paradigm, collaborative decision making, will offer conceptual and practical solutions at the systemic and patient/clinician level. Collaborative decision making is tailored for populations like people with SMI and other groups who experience chronic and complex symptoms, along with power imbalances within health systems. Advancing from shared decision making to collaborative decision making clarifies the mission of the model: to facilitate an empowering and recovery-oriented decision-making process that assigns equal power and responsibility to patients and clinicians; to improve alignment of treatment decisions with patient values and priorities; to increase patient trust and confidence in clinicians and the treatment process; and, in the end, to improve treatment engagement, satisfaction, and outcomes. The primary purpose of collaborative decision making is to increase values-aligned care, therefore prioritizing inclusion of patient values, including cultural values and quality of life–related outcomes. Given the broad and constantly changing context of treatment and care for many people with SMI (and also other groups), this model is dynamic and continuously evolving, ready for use across diverse contexts. Implementation of collaborative decision making includes increasing patient knowledge but also patient power, comfort, and confidence. It is one tool to reshape patient-clinician and patient-system relationships and to increase access to value-aligned care for people with SMI and other groups.

Keywords: collaborative decision making, patient-centered care, patient-provider communication, serious mental illness, shared decision making

Shared decision making is a recovery-oriented and person-centered approach that includes patients in the treatment-planning process. Stakeholders across health care domains are increasingly invested in shared decision

making, though implementation in mental health practice faces obstacles.¹ Shared decision making typically includes three steps: (1) the patient describes the problem; (2) the clinician assesses the patient, describes the treatment options, and provides clinical expertise; and (3) the two (or more, if family or others are involved) discuss and come to a consensus about the treatment decision.^{2,3} When effectively implemented, shared decision making is associated with improvements not only in treatment adherence, engagement, and satisfaction, but in social functioning, quality of life, and clinical outcomes,⁴ resulting in enthusiasm for this approach among clinicians, patients, and others. Despite that enthusiasm, however, shared decision making is not implemented consistently and effectively in mental health care and is especially challenging in treatment settings for serious mental illness (SMI). In this Perspectives article we discuss two sets of barriers to implementing traditional shared decision making, particularly in SMI services. We then propose a novel paradigm, *collaborative decision making* (CDM), which has the promise to advance shared decision making and to increase patient-clinician collaboration in mental health settings.

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IMPLEMENTATION BARRIERS TO SHARED DECISION MAKING AT THE PATIENT/CLINICIAN LEVEL

Shared decision making originally emerged from the medical field with the intention of maximizing quality of life and ensuring that treatments are aligned with patient values.⁵ Presently, stakeholder perspectives greatly vary on the primary purpose of shared decision making. The most frequently cited goals are the following: to increase alignment of decisions with patient values and priorities (i.e., patient-centered or recovery-oriented care);⁶ to improve patient engagement in decision making (i.e., patient activation);⁷ and to increase adoption of, and adherence to, empirically supported treatments (i.e., best practices).⁸ For example, nurses in inpatient mental health tend to focus on informed consent and treatment adherence, aligning with a best practices model,⁹ whereas patients prioritize having a meaningful “voice and choice,” aligning with recovery-oriented care.^{1,6} It is therefore not surprising that there are marked discrepancies in how clinicians and patients understand, define, and use shared decision making and related concepts, such as patient participation in treatment.

Clinicians tend to highly endorse shared decision making, and they commonly report that additional investment in it is unnecessary because they already use it.^{10–12} When asked to define shared decision making and their use of it, they report a list of relevant but incomplete activities such as asking patients if they have questions and providing them information about their medications or their diagnosis.^{12,13} A robust back-and-forth discussion about the decision itself is rare; for example, one study found that only 14% of appointments included interactions indicating patient-provider partnership in decision making.¹⁴ Patients with SMI are more likely to be excluded from shared decision-making practices, as clinicians report not using these practices with patients who have high symptom severity or cognitive impairments.^{12,13} The available evidence shows significant heterogeneity, however, in decisional capacity among people with SMI¹⁵ and that—with appropriate accommodation, such as more time and aid materials—people with decisional impairments can be meaningfully involved in decisions.^{16–18}

Additionally, treatment plans rarely reflect shared decisions. One study, for example, found that decisions explicitly incorporated the patient’s preference only 22% of the time.¹⁹ And about half of the time, clinicians do not accurately identify why patients with SMI came to an appointment,²⁰ making it impossible for the clinician to come to a treatment decision that aligns well with the patient’s presenting problem. Therefore, there are fundamental gaps in the communication that is essential for making accurate and shared treatment decisions, and these gaps limit the clinician’s ability to identify patient preferences and act upon them. These gaps may be exacerbated by disagreements about what treatment goals should be prioritized;^{21–23} for example, patients often are most interested in being able to participate in valued activities and associated functional goals, whereas clinicians are often most interested in reducing clinical and cognitive

symptoms. These discontinuities between clinicians and patients at the conceptual and interactional level create implementation barriers to improving any of the potential goals of shared decision making.

IMPLEMENTATION BARRIERS TO SHARED DECISION MAKING AT THE SYSTEMIC LEVEL

The most substantial barriers to shared decision making are at the systemic level. One of these barriers cuts to the root of the shared decision-making concept, which posits that increased patient access to information is the key to improved communication and outcomes. Increasing patient knowledge about topics, including treatments and diagnoses, is necessary but not sufficient for fruitful patient-clinician interactions. Increased patient power is also required.²⁴ Patients need both knowledge and power to be confident and comfortable enough to engage in treatment decision-making processes. Most patients are well aware of the overall history and limitations of the current mental health system, especially for people in marginalized groups, those living in poverty, and those with more significant psychiatric symptoms, all of whom are over-represented in the SMI population.^{25–27} Patients often have their own iatrogenic treatment experiences in the system and carry the resulting trauma and fear into interactions with new clinicians. Due to their own experiences, the broader context, or both, they may not feel comfortable enough to speak up and engage in shared decision making even when they have a positive relationship with their current clinicians.²⁸ The current paradigm has not sufficiently addressed the underlying context of systemic power imbalance for people with SMI,²⁹ which is a prerequisite of engaging in and implementing shared decision-making strategies effectively.

There are a number of other systemic obstacles to implementing shared decision making, including time limitations, staff turnover and training needs, access to decision aids and other resources, and health system buy-in.^{11,30–32} In the current U.S. health system and many others internationally, clinicians and institutions are generally not compensated for high quality of care, which could otherwise foster broad systemic investment in patient engagement in decision making, given its connection with improved treatment engagement, satisfaction, and outcomes. Instead, compensation is often based on the number of patients seen, which facilitates short appointments, clinician burnout, and patient disempowerment. This system particularly affects patients with SMI because of common practices like polypharmacy,³³ which can cause cognitive impairments due to anticholinergic burden and other processes³⁴—thereby making it difficult to speak up at all, let alone in short, rushed appointments.

Additionally, there is a lack of fit between many current shared decision-making interventions and the needs of the SMI population. A range of shared decision-making interventions are available—some of which show efficacy, though many are for other populations.⁴ The most common of the potentially useful interventions for the SMI population are decision

aids and other decision-support tools, which increase access to knowledge and which help weigh pros and cons, usually for two to four specific options. These types of aids are best suited to treatment decisions where only a small, specific number of evidence-based choices are available for a given presenting problem—for example, whether to take an antidepressant during pregnancy.³⁵

For populations with complex and chronic conditions that include SMI, however, many decisions are not well suited to this approach. Many of the decisions for these populations focus on quality of life rather than implementation of best practices. These decisions can relate to questions such as where to live or whether to have a guardian, and if so, who it should be. These types of decisions may present wide-ranging, complex, contextual (i.e., dependent on the person and location), and interrelated options. Given the sheer number of clinicians, treatment teams, and treatment decisions that may be involved in the care of those with SMI, any intervention that is based around a single clinician, institution, clinician, or type of decision will necessarily be constraining. That said, any decisions made will inescapably involve trade-offs; it is unrealistic to expect that every dimension of care can be optimized at once.

Perhaps the most important practical obstacle is that many of these interventions are currently difficult for patients and clinicians to access, usually requiring institutions to purchase tools, implement systems, or provide training. Since institutional buy-in and implementation are inconsistent, some stakeholders have no way of accessing any intervention. Patients have no support in initiating a more engaged decision-making process themselves. As described above, clinicians face a number of obstacles to initiating shared decision making, and frequently conceptualize it differently than their patients. When patients initiate collaborative processes, however, clinicians generally react positively, and decisions are more likely to reflect patient preferences, indicating that supporting patient-initiated and -driven collaboration is effective.^{19,36,37} Current rates of patient initiation are low, however, and placing responsibility on patients to change imbalanced power dynamics without resources or assistance is unreasonable. Patient gaps in knowledge or skill sets (e.g., lack of knowledge about options, impaired communication skills), as well as lack of comfort and confidence, as previously noted, decrease the likelihood that many patients will change this dynamic without support.

PUSHING THE PARADIGM FORWARD: COLLABORATIVE DECISION MAKING

To address these challenges, we propose a new, tailored form of shared decision making: *collaborative decision making*.³⁸ CDM assigns equal power and responsibility to patients and clinicians across all aspects of decision making, empowering patients and facilitating better decision making based on patient values and preferences. Table 1 identifies the existing barriers to shared decision making and details the ways in which CDM attempts to address them.

Separate from the specific differences presented in Table 1, CDM is different from shared decision making in five key respects:

- *CDM explicitly grants equal power to patients* in the decision-making process, including making the final decision. The expectation is not that every decision made will be a patient’s first choice but that the patient will be meaningfully and powerfully involved in all decisions. This can include the use of psychiatric advance directives, joint crisis plans, and other means. We use the language “equal power” to communicate the power balance in the “big picture”—within both the patient × clinician dynamic and patient × system dynamic, and across many decisions and interactions. Power is a dynamic, rather than static, process. It is unlikely to remain exactly equal at all times throughout decision making, and in certain situations, aiming to equalize power would potentially be inappropriate or unnecessary. As an example, a patient may be the only appropriate decision maker regarding the choice of a male or female therapist.
- *Via their equal power, patients identify their preferences for the structure of the decision-making process itself*, including their own preferred role (which includes declining to participate) and determining which other partners to involve—if those other partners consent.
- *CDM recognizes the responsibility that comes with decision making*. Given that each decision made matters and may affect the patient significantly, all decision-making participants must carefully consider their own reasoning and the input of others before arriving at a final position.
- *CDM endorses the values-aligned model of decision making*, prioritizing patient values and quality of life as key components and goals of the decision-making process. CDM is still interested in promoting high-quality care via best practices and patient activation, but these goals cannot be prioritized above value alignment.
- *CDM is a dynamic and evolving decision-making approach*, rather than having three approximate steps like shared decision making. This is a better fit for a broad and constantly changing context of treating SMI and other chronic disorders.

CDM, in addition to increasing patients’ knowledge about options or outcomes, increases patients’ beliefs in their ability and authority to participate, their confidence in their knowledge and skills associated with the encounter, and their trust that their engagement in decision making will have positive outcomes regardless of the ultimate treatment decisions made. For clinicians, CDM increases their knowledge of each patient’s background, goals, values, and preferences in order to guide an effective, individualized decision. It also increases their confidence and skill in being a collaborative partner during the decision-making process, improves capacity to listen and to jointly solve problems rather than making decisions

Table 1		
Key Barriers to Implementing Shared Decision Making Among People with Serious Mental Illness and Solutions Offered by Collaborative Decision Making		
Level	Barriers to implementing shared decision making	Solution offered by collaborative decision making
Patient/clinician	Lack of consensus about primary purpose Goals vary between and among stakeholders	Explicit purpose is to increase alignment of decisions with patient values and priorities (i.e., patient-centered or recovery-oriented care)
Patient/clinician	Clinicians focus on providing information and answering patient questions, whereas patients prioritize having a meaningful voice and choice	Emphasize equal power for patients and treatment team Frame decision as collaborative to clarify emphasis on patient voice and choice
Patient/clinician	Typical steps of shared decision making assume clinician initiation, but patient initiation is a more successful approach	Process is dynamic Prioritize patient-led interventions to increase patient initiation Patient can define how decision-making process will occur
Patient/clinician	Clinicians may not offer shared decision making to patients who are perceived to be “too” symptomatic or cognitively impaired	Increase patient initiation of collaborative process
System	Current concept does not reckon with history and context of mental health system Patients need knowledge and power to engage in treatment decision making Patients may not engage in decision making with providers whom they trust, due to past negative experiences in mental health system	Work to realign context of treatment decision making through empowerment and systems change Patients have equal power and responsibility over decision-making process Patients define steps decision-making process to occur (including abstaining) Actively work to increase patient trust, confidence, and comfort
System	Institution- and clinician-related obstacles to implementation (e.g., cost, time, and other resources; health system buy-in)	Patient-led interventions are prioritized Interventions are “designed for dissemination,” including high feasibility and generalizability
System	Populations with complex and chronic conditions like serious mental illnesses often have treatment decisions with many, context-specific options and no clear best practice The most common and evidence-based interventions are not a good fit	Interventions are designed to focus on facilitating the decision-making process and increasing collaboration, rather than focusing on specific decisions Interventions help identify personal values and priorities to increase quality of life Frame decision making as ongoing and dynamic
System	Interventions are currently difficult to access Patients and clinicians typically rely on institutions to access	Interventions are designed so that patients and clinicians can access them with minimal reliance on institutions
System	Interventions typically focus on increasing access to information and rarely include increasing patient power, comfort, and confidence	Interventions enhance power, comfort, and confidence of patients—which includes acknowledging and realigning the decision-making process, broader systems advocacy and empowerment, and increasing targeted knowledge and discrete skills to facilitate initiation and engagement in decision making and related processes

unilaterally and authoritatively when perspectives differ, and expands their understanding of the expertise relevant to making treatment decisions and of who holds that expertise. We posit that these domains are all improved via CDM over time and that, as patients feel heard and empowered, they will have more positive and collaborative interactions with their clinicians. CDM is not a quick solution but an iterative process. Across these domains, CDM can help to reshape patient-clinician and patient-system relationships to maximize

patient empowerment, engagement, respect, and access to value-aligned treatments.

Power is held not only by patients, clinicians, and other individual stakeholders participating in a specific decision but also by systems—for example, in the policies and processes implemented, and in the messages communicated to all stakeholders. Multiple avenues must be pursued in order to increase patient power, and therefore CDM, by increasing access to power and by transitioning power to patients from

systems and from other stakeholders in the decision-making process. Increasing patients' knowledge, skills, comfort, and confidence, as previously noted, can increase their ability to harness the power that patients may already have access to but not actually use. CDM interventions that increase access to information, that change patient-clinician dynamics, and that increase self-empowerment and self-advocacy may improve patient power by facilitating their ability to initiate more

collaborative and equal patient-clinician relationships—a strategy that many clinicians are responsive to.^{36,39} Clinician training that includes explicit discussion of power dynamics and ways to transition power to patients while remaining an effective and conscientious treatment provider may help clinicians to overcome their concerns and to gain skills. Institutions as a whole may require broad assessment and restructuring of values to aid these goals. This effort may include reflection on current

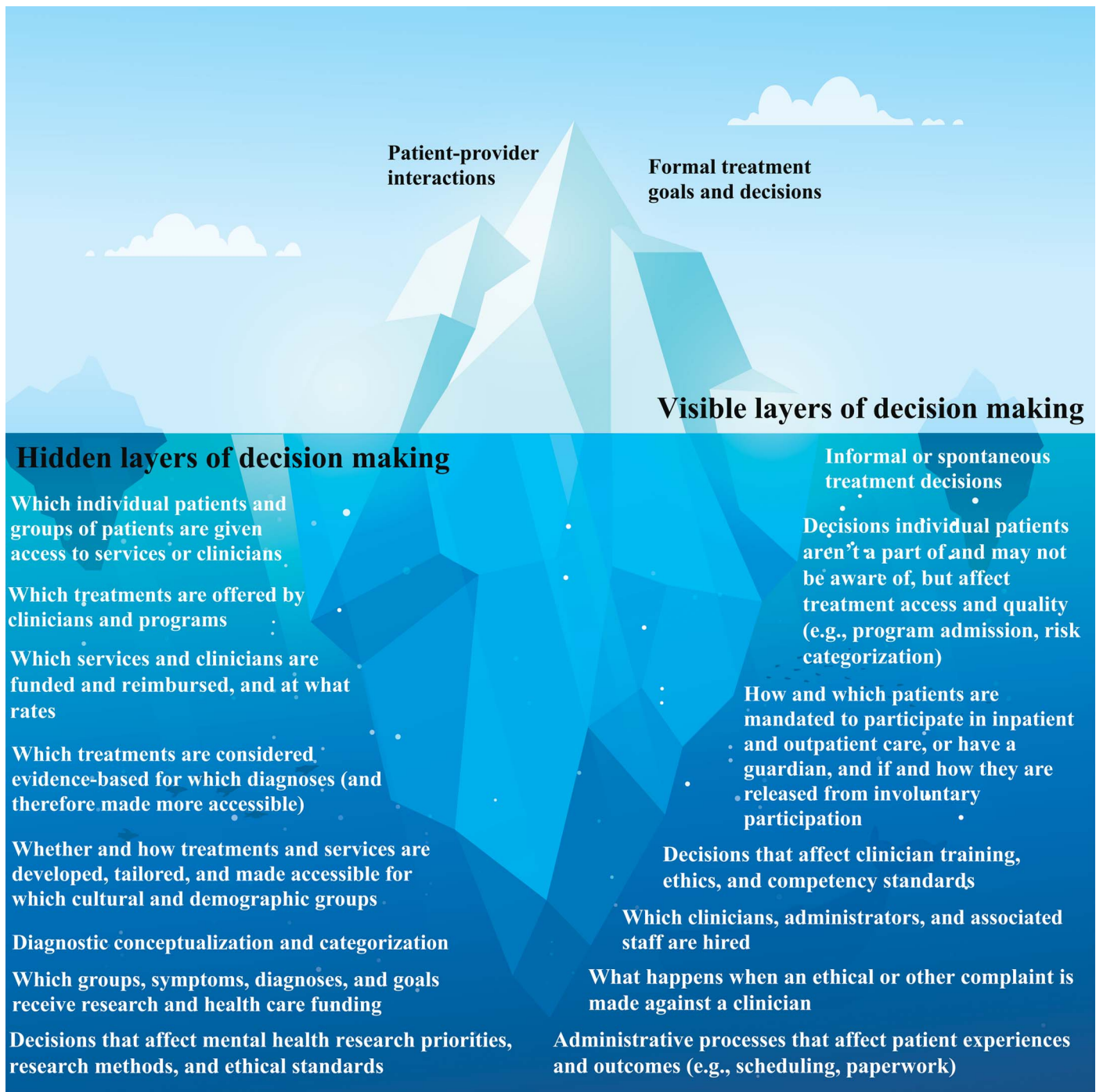


Figure 1. The collaborative decision-making paradigm.

attitudes and beliefs about patients and the patient role, and may involve work to adjust these attitudes and beliefs in order to improve patient power and, ultimately, treatment quality. Associated structures that affect patient access to power, like health inequity and the impact of racism, sexism, and other isms on access and quality of care, will require action to implement CDM in all groups and contexts. Identification of implementation barriers and facilitators, along with structural adjustments based on these, may help institutions increase CDM.

Therefore, we conceptualize CDM as a paradigm that affects all levels of mental health care—that is, from the individual patient level, through discrete patient-clinician interactions, to a macro patient-system context. It is important to acknowledge, however, that the level where CDM can be most easily observed and therefore evaluated and improved happens at the patient-clinician interaction level. At the same time, these interactions do not happen in a vacuum. They are influenced by individual patient and clinician factors, as well as by system-level factors, including decision-making processes that, at present, patients rarely if ever have access to⁴⁰ (see Figure 1). For example, a patient cannot engage in a collaborative decision about participating in a treatment that is inaccessible to that patient because of institutional factors.

Collaborative decision making as a name for this new paradigm was chosen intentionally. *Shared decision making* is typically initiated by the clinicians, who usually maintain sole decision-making control over fundamental aspects of the decision that they see as falling under professional expertise, such as choosing a medication or therapy: it is not truly “shared” in many cases. Clinicians often “share” useful information about treatments with patients, though they rarely “collaborate” during the decision-making process itself.^{12,14} Using *collaborative* explicitly communicates that the process is intended to be reciprocal and “collaborative” throughout rather than completed by one party and then communicated or “shared” with everyone else afterward. Adjusting the name of the process helps improve understanding of how it works and what it accomplishes, which is particularly important for stakeholders who may not be familiar with it. CDM also reflects broad developments being made by many in the mental health field to promote patient empowerment and inclusion of patient values in treatment decisions.^{11,19,24,41}

WHY COLLABORATIVE DECISION MAKING MUST BE A VALUES-ALIGNED PARADIGM

We recognize two potential concerns about our proposal; we would therefore like to present additional reasons in its support. First, a common concern about increasing patient involvement in decision making is that appointment times in mental health systems, already strained in most countries, will need to be extended.¹⁰ Although that is possible, a prior review found that integrating decision aids or strategies to increase patient participation in decision making increased appointment times by a median of 2.5 minutes (range, –8 to +23 minutes).⁴ Moreover, alignment of treatment decisions

with patient goals and values decreases patient attrition from treatment.^{8,42} Therefore, initial short-term, small-time investments may lead to a long-term time savings because patients need fewer appointments to find appropriate and lasting effective treatments. Decreasing attrition and improving appropriate treatment personalization also decrease burden in other parts of the mental health system by decreasing crisis service needs.

Second, we understand that some stakeholders may understandably advocate for the “best practices” approach to decision making. Values alignment and best practices should be mostly congruent with each other because identifying and aligning with values is one of the “legs” of the evidence-based practice “stool.”⁴³ Prioritizing values and patient voice during decision making is necessary because it increases the ability to bridge the current gap between clinicians and patients in accurately identifying patient goals and priorities, and then in making well-fitting treatment decisions. Moreover, among patients with SMI, a single “best practice” treatment may not exist. Give that questions of quality of life and complex cost-benefit ratios are common, a focus on patient values makes for an excellent fit.

In some instances, of course, the best research evidence or the clinician’s judgment will be at odds with patient values and preferences. Further, in some other instances, decisions aligned with patient values and preferences may increase the risk to the patient in some areas or decrease the likelihood of benefit in other areas. We argue that acceptance of these risks is necessary to increasing patient power and improving the dynamic of treatment decision making and of mental health contexts more broadly. Further, the risks and benefits most important to patients may differ from those most important to clinicians.^{21,22,44} That is, for example, a patient may more highly value having better cognitive performance or sexual drive rather than having fewer delusional thoughts or decreased mood symptoms, whereas a clinician may have opposite values. Likewise, a patient may prefer a treatment that is relatively higher risk in critical areas (e.g., suicide risk). Movement away from the paternalistic model of decision making and mental health practice means patients are treated as stewards of their own lives who, with informed consent, can take on significant risk if they judge it worthwhile and aligned with their values and goals.

Third, only the values-aligned approach actually pushes the patient-oriented paradigm forward in terms of promoting recovery-oriented care and redistributing power in the mental health system. The recovery movement emphasizes the empowerment of groups who have not historically had a say in treatment or in the mental health system in general.^{6,45} Studies continue to find that rates of shared decision making are lowest for people with psychotic disorders, and that patients who have experienced involuntary treatment are most likely to report lower rates of shared decision making than their therapists.⁴⁶ Perez Jolles and colleagues’ systematic review of minority patients²⁸ further supports the view that empowerment of historically and presently marginalized patients requires clinicians to employ more-engaged decision making; even when individual clinicians use broadly effective

patient-engagement practices, it may take some time for patients to move beyond their past negative experiences with other clinicians and their distrust of the system as a whole. Values alignment supports empowerment and acknowledges that our current data on best practices do not always effectively represent minority populations or countries outside of North America and Western Europe; consideration of local, cultural, and personal values is therefore needed to increase the likelihood of treatment engagement and effectiveness.

IDENTIFYING AND DEVELOPING IMPLEMENTATION-READY COLLABORATIVE DECISION-MAKING INTERVENTIONS AND TOOLS

Following adoption of CDM, we can then also identify interventions that work, taking into account the obstacles identified above. Based on these and the existing literature, we propose that CDM interventions and tools have the capacity to facilitate patient initiation of CDM through increased access to relevant knowledge and skills, and to increase patient power, confidence, and comfort in the decision-making context using a recovery-oriented and patient-centered model. Additionally, interventions that are highly generalizable across many decisions, settings, and treatment team members (including family members) and those that are minimally reliant on institutions to provide access are prioritized. By contrast, when decision aids, clinician training, or similar resources are incorporated within a set of narrow or focused strategies, the above aims are unlikely to be achieved. For example, although the Option Grid decision aids are helpful tools,⁴⁷ using them as their own would be a shared decision-making intervention and not a CDM intervention; such tools are designed to aid patients and other stakeholders in making very specific treatment decisions (e.g., whether to get a lumpectomy with radiation or a mastectomy for early-stage breast cancer), not to serve the broader aims of CDM.⁴⁸

If existing interventions are already aligned with CDM's principles and the components we propose, or are adapted to be so, this alignment could be incorporated into a strategy for pushing the paradigm forward. For example, Alegria and colleagues' DECIDE intervention⁴⁹ fits these parameters because DECIDE uses a culturally aware skills-training model to improve patient-clinician communication and collaboration, including active patient participation in treatment decision-making processes. DECIDE has shown evidence of efficacy for non-SMI minority populations in behavioral health settings.

Deegan and colleagues' CommonGround intervention for people with SMI fits many of these parameters⁵⁰ because CommonGround prioritizes what it calls *personal medicine*,⁵¹ the activities that individual persons see as giving their lives meaning and pleasure. CommonGround helps each patient identify his or her own personal medicine, and facilitates patient discussion with psychiatrists and other medication managers to ensure that medication choices support personal medicine and other factors that support an individual patient's recovery. CommonGround has faced some of the implementation barriers described here, however, and requires substantial

institutional buy-in.³¹ Adaptation of CommonGround to overcome those barriers may be appropriate.

Finally, Collaborative Decision Skills Training⁵² is a brief group intervention for people with SMI that is intended to facilitate patient knowledge, skills, comfort, and confidence in initiating and engaging in CDM. This intervention is aligned with the CDM model because it uses an empowerment-based skills-training model to support patients to change the patient-clinician decision-making process so that it works effectively for each individual patient. It also includes discussion of advocacy at a broader level, setting the stage for patients who want to pursue CDM at a more systems level (e.g., advocating for an evidence-based intervention to be offered in the treatment program they are participating in). The pilot demonstrated feasibility and showed initial evidence of effectiveness.⁵²

CONCLUSION

Advancing from shared decision making to collaborative decision making clarifies the mission of the model: to facilitate an empowering and recovery-oriented decision-making process that assigns equal power and responsibility to patients and clinicians; to improve alignment of treatment decisions with patient values and priorities; to increase patient trust and confidence in clinicians and the treatment process; and, in the end, to improve treatment engagement, satisfaction, and outcomes. CDM paves the way toward actionable interventions and other implementable steps that contribute to a mental health care system that prioritizes patient empowerment and respect alongside access to high-quality care. To be aligned with this model, interventions must increase relevant knowledge and power, facilitate patient-initiated collaboration, be feasible for usual-care settings, and be generalizable across a wide range of decision-making contexts.

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