

Shared decision making in mental health: prospects for personalized medicine

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This paper describes the shared decision-making model, reviews its current status in the mental health field, and discusses its potential impact on personalized medicine. Shared decision making denotes a structured process that encourages full participation by patient and provider. Current research shows that shared decision making can improve the participation of mental health patients and the quality of decisions in terms of knowledge and values. The impact of shared decision making on adherence, illness self-management, and health outcomes remains to be studied. Implementing shared decision making broadly will require re-engineering the flow of clinical care in routine practice settings and much greater use of information technology. Similar changes will be needed to combine genomic and other biological data with patients' values and preferences and with clinicians' expertise. The future of personalized medicine is clearly linked with our ability to create the infrastructure and cultural receptivity to these changes.

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The current complexity of treatments and outcomes in modern medicine presents a fundamental dilemma. Few medical treatment decisions involve a clear best choice; the typical medical decision involves tradeoffs among multiple partially effective interventions with different risks. Consider the case of surgical interventions. Placing a pin in a fractured hip represents a rare case of a consensual best treatment for almost every patient. In many other common surgical situations, the evidence is considerably more complicated. For example, surgery for benign prostatic hypertrophy produces better urine flow at the risk of incontinence and impotence. When men understand the tradeoffs accurately, many prefer medications or watchful waiting.¹ Similarly, for early breast cancer, spinal disk injury, prostate cancer, rotator cuff injuries, uterine fibroids, coronary artery disease, and many other surgical conditions, choice among different interventions with complex outcomes and adverse effects is the rule.² This fundamental dilemma gives rise to the belief that patients should be involved in making medical decisions generally, and to the paradigm of shared decision making more specifically.

Shared decision making assumes that two experts (or teams of experts) should collaborate in making complex medical decisions.³ The health care provider (often a team of professionals) brings expertise in understanding the medical problem, the possible interventions, and the potential benefits and risks of alternatives. The patient

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(often assisted by family or support network members) brings expertise related to understanding the individual's values, goals, supports, and preferences. Shared decision making generally involves both partners presenting their respective views and then negotiating a plan that both agree is ethical, consistent with the evidence, congruent with the patient's preferences, and practical. Conceptually, shared decision making falls between two extreme approaches to medical decision making: the paternalistic and the autonomous decision models.⁴ In the traditional, paternalistic model, the physician assesses what is best for a particular patient, based on scientific evidence and clinical judgment, and makes the decision. In the autonomous decision model, the patient is presented with information, weighs the information, and makes the choice unilaterally.

As a simple example of shared decision making, consider a young woman who suddenly develops radiating pain as a result of a back injury. Her medical exam and magnetic resonance imaging reveal a lumbar disk protrusion. Her physician describes alternative approaches that include surgery, nerve blocks, a back brace, physical therapy, and watchful waiting. The patient and her parents are averse to surgery, especially when they understand the risks, and prefer conservative treatment. The physician agrees that wearing a brace and waiting for 2 months to re-evaluate the injury is reasonable. Two months later, she is much improved, and they agree that exercise is the best strategy.

Now consider a more complex decision. A second young woman develops a breast lump and is diagnosed with uncomplicated early breast cancer. Her physician reviews with her the surgical alternatives (lumpectomy vs breast removal) as well as adjunctive chemotherapy and radiation therapy, and describes the risks and benefits of each. Due to the early stage of illness, the physician clearly believes that the patient is an excellent candidate for lumpectomy. Because of a strong family history and the experience of watching her mother die of breast cancer, however, the young woman prefers bilateral mastectomy. After further discussion with the patient and her husband, the physician understands and accepts the patient's decision and performs the more radical surgery. In this case, the physician initially disagrees with the patient's choice but accepts the patient's preference and right to make the decision.

The medical literature and research evidence on shared decision making, decision supports, and decision aids are

extensive and growing rapidly.⁵ For example, there are now literally hundreds of decision aids to help patients make medical decisions. The diversity of these instruments has led recently to the development of international standards.⁶ The evidence shows that decision aids help patients to make more informed decisions that are more congruent with their values and preferences.⁷ Longer-term effects on basic health outcomes are not yet well studied.

Shared decision making in mental health: current status

Several arguments suggest the importance of shared decision making in mental health. First and foremost, effective mental health care should be person-centered.^{8,9}

As is true with other long-term illnesses,^{10,11} empowering people to be knowledgeable and active in managing their own mental illnesses is critical.¹² Decisions related to chronic illnesses differ from acute-care decisions in several ways: for example, there are many opportunities to make and revisit the decisions, and the patient must take much greater responsibility in carrying out decisions daily.¹⁰ Because of personal values and subjective responses, patients themselves can best evaluate trade-offs in efficacy and side effects.^{13,14} In mental health, shared decision making enhances the working relationship needed to optimize long-term outcomes.¹⁵ For example, learning to manage one's illness with medications involves a dynamic, longitudinal process that encompasses resolving decisional conflicts, conducting experiments, balancing positive and negative effects, and making changes. A close working alliance between practitioner and client is the sine qua non of success.

In addition to these practical concerns, others have made ethical and legal arguments for shared decision making. Autonomy—the right to make decisions regarding one's body—has long been a fundamental principle of Western medical ethics.¹⁶ Recognizing the importance of autonomy, the legal standard for medical care is shifting from informed consent to informed choice among reasonable alternatives.¹⁷

Most mental health patients express a desire to participate in making decisions regarding medications and hospitalizations.¹⁸⁻²¹ Nevertheless, shared decision making is not prominent in widely disseminated psychiatric medication algorithms²² and not usually practiced in daily medication management.¹⁵ Patients with severe and per-

sistent mental illnesses report that their perceived role in making medical decisions is usually passive.^{18,21,23} Further, many psychiatrists consistently report that shared decision making is not applicable to decisions regarding medications and hospitalizations due to patients' decisional incapacity.^{24,25}

At the same time, the evidence in support of shared decision making in mental health is expanding rapidly. First, nearly all psychiatric patients, even the great majority of those with the most severe disorders such as schizophrenia, are capable of understanding treatment choices and making rational decisions.²⁶⁻²⁸ Like many other patients with limited education, learning disorders, or other disadvantages, some require repetition of information or multimodal sources of information.²⁹ Also, some psychiatric patients experience temporary decisional incapacity, such as during psychotic episodes, and may elect to establish psychiatric advanced directives to cover such periods of decisional incapacity.³⁰

Second, shared decision making constitutes a core principle of many effective mental health practices and may, in part, explain their effectiveness.^{12,31-33} For example, honoring the client's preference for type of job is a fundamental principle of supported employment, and the entire model follows the client's decisions about when to search for a job, how many hours to work, whether or not to disclose illness to the potential employer, supports on the job, manner of follow-up, and so on.³⁴ Emphasis on shared decision making is also built into illness management and recovery,¹² behavioral family therapy,³⁵ integrated dual disorders treatment,³⁶ and systematic medication management.³⁷ Assertive community treatment, which was historically criticized for paternalism, is also becoming more client-centered.³⁸

Third, although research on shared decision making in mental health is in its infancy, seven initial randomized controlled trials support its effectiveness. Malm et al³⁹ provided multiple shared decision-making sessions within a treatment program for schizophrenia patients, and found that the experimental group had higher ratings of patient satisfaction than controls at 2 years. Van Korff et al⁴⁰ provided multiple sessions of shared decision making to depressed patients, and found better adherence and depression symptom outcomes favoring experimental over control participants at 3, 6, 9, and 12 months. Van Os et al gave one session of shared decision making to patients with schizophrenia and their doctors in a randomized clinical trial and found that the experimental

patients reported improvements in quality of patient-doctor communication and that the intervention induced changes in medication management immediately.⁴¹ Hamann et al⁴² conducted a randomized controlled trial with schizophrenia inpatients and found increased knowledge and perceived involvement in decisions by the experimental group during hospitalization. Priebe et al⁴³ used a cluster randomized design to study use of a computer-mediated intervention to structure patient-clinician interactions regarding quality of life and needs for care every 2 months for a year. Schizophrenia patients in the experimental group had better subjective quality of life, fewer unmet needs, and greater satisfaction with treatment at 1 year. Loh et al⁴⁴ used a cluster randomized design to study a shared decision-making intervention with depressed patients. At 6- to 8-week follow-up, experimental group patients reported greater participation in decision making and greater satisfaction with care, although the intervention did not impact severity of depressive symptoms. Joosten et al⁴⁵ used a cluster randomized design to study shared decision making within inpatient addiction treatment programs. Patients who received shared decision making rather than traditional decision making had greater reductions in drug use and psychiatric symptoms at 3-month follow-up. Woltmann⁴⁶ used a cluster randomized design to study shared decision making during one session of treatment planning between case managers and clients with severe and persistent mental illnesses. Clients and case managers in the shared decision-making group were more likely to report that decisions were collaborative.

Thus, as in general medicine, the initial research in mental health shows that shared decision making increases the quality of decisions (knowledge, participation, and congruence with values), but there is minimal evidence regarding objective health outcomes. Long-term studies of health outcomes related to greater knowledge, participation in illness self-management, and better relationships with practitioners need to be evaluated.

The doctor's role in shared decision making

In this section, we illustrate some of the barriers to implementing shared decision making in mental health by examining the outpatient psychiatrist's role. The central point is that practising shared decision making involves much more than endorsing the concept. The complex structure and process of care must support the desired

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practice. To achieve shared decisions, psychiatrists and patients need significant time,⁴ facilitated communication,⁴⁷ and easy access to clinically useful current scientific knowledge.⁴⁸ These conditions do not currently exist in psychiatric office practice in the US. Therefore, the process of care will need to be redesigned to make shared decision making the easy and natural way to practice.⁴⁹ Psychiatric office visits are complex and dynamic interactions that are packed with psychological, interpersonal, and practical tasks. These include establishing a trusting relationship; identifying goals for the encounter; gathering needed information, such as assessing and addressing symptoms, function, and/or side effects of treatment; planning the next steps; documenting the encounter; prescribing medications; communicating with other providers; and filling out forms.⁵⁰ The time for shared decision making must come from time usually spent on these other tasks because expanding visit length is currently prohibited by costs.

Addressing the time dilemma will require re-engineering office practice and using information technology.⁵¹ At the microsystem level, a trained and organized team (an activated patient, support from other staff, and a well-designed information system) can create efficiencies in the flow of the office visit.⁵² Team members other than the psychiatrist can elicit and record the patients' current concerns, experiences, and values.⁵³ They can also obtain required vital signs, track down lab values, fill out sections of forms the psychiatrist needs to sign, prepare prescriptions for physician review and signature, and help the patient to be as active as possible, including direct participation in collecting information through patient portals to the electronic medical record. A well-designed electronic medical record can increase efficiency (and improve care) by collecting and graphically displaying patient-entered information, laying out evidenced-based treatment algorithms, and streamlining common required tasks such as clinical documentation, prescription writing, and clinical communication to other health care providers.⁵⁴

Many people, including both those with and without psychiatric symptoms, find it difficult to express themselves in doctors' offices. The medical care process is not transparent, and people do not naturally know what information is relevant and important to communicate. Further, medical settings are often intimidating, and people are nervous. Nevertheless, the voice of the patient must be at the heart of the decision-making process. Without hearing the patient's chief current concerns, subjective life

experiences, and core values, decisions lack both data and salience to the patient's life.⁵⁵

Currently, all information about the patient's perspective comes from the dialog between the psychiatrist and the patient during the busy office visit. Important issues, such as whether the patient's chief concerns for the session are routinely elicited and whether the patient experience is gathered in a valid, reliable manner, are up to self-designed practice habits of the psychiatrist.⁵⁵ Without a system designed to elicit, organize, and amplify the voice of the patient, the psychiatrist can easily miss information that would make the clinical decisions much more informed, relevant, and collaborative.

Re-engineering the office could facilitate communication in three ways. First, the redesign could increase the confidence and ability of patients to be active participants in the care process by explicitly welcoming them when they arrive for service, orienting them to the care process, and providing accessible education on the illnesses and the treatment options. Second, the patient's voice could be amplified by explicitly eliciting and documenting chief concerns, experiences, and core values. If this inquiry occurs before the actual encounter, the information is more likely to be complete, the patient's questions will be written down so they are not forgotten, and the visit time is freed up for double-checking understanding and for in-depth discussion. Finally, symptoms, medication side effects, and functional status questions can be asked in a systematic fashion using standardized instruments by computer,^{55,57,58} and the longitudinal results can be displayed graphically. Computerization allows the patient and the psychiatrist to examine progress and base discussions on longitudinal standardized data as a team, practicing individualized evidence-based medicine.

The essence of evidence-based practice is to use knowledge gained through research to inform specific clinical choices. Decision supports are more likely to be used if information is available in the regular flow of the office visit. Connecting the patient and the psychiatrist with the evidence at the time that it is needed and in a form that both can understand is therefore another critical element of redesigning the office visit to facilitate shared decision making.⁴⁹

Both patients and psychiatrists need timely access to research findings. Patients can benefit from orienting information about the illnesses and what is known about options to minimize symptoms and maximize function. Psychiatrists and patients together can benefit from

research-supported charts and algorithms that condense whole fields of knowledge into research-supported paths for care.^{59,60} Psychiatrists also need direct access to detailed information when it is too voluminous or complex to remember. Currently, this includes decision support in the form of drug-drug interactions that appear as safety warnings in electronic records. Soon, it will encompass individualized medicine: historical, medical, physiological, and genetic information that will summarize patient-specific risk factors.

The needs of people with severe and persistent mental illnesses do not vary radically from site to site. Therefore, a transformational psychiatrist office visit process that weaves together all the elements that are needed for efficient evidence-based psychiatric practice could be designed, tested, packaged, and implemented widely. Doing so shifts the office visit process to one that is specifically designed to meet the needs of people who have an ongoing psychiatric illness or vulnerability using principles that have been shown to be helpful in improving the care of people with other persistent health difficulties.⁶¹

Personalized mental health care and shared decision making

Creating a flow of care that makes sharing decisions natural and efficient will be even more important when we have access to tests that will provide us with person-level information that is relevant to mental health care decisions. The current state of treatment selection in mental health is characterized by multiple choices, with little evidence to guide decisions to select initial or subsequent treatments.^{62,63} Genetic or molecular factors might help inform treatment selection by identifying a priori people likely to have side effects, such as treatment-emergent suicidal ideation in response to antidepressants,⁶⁴ or metabolic syndromes with antipsychotic treatment.⁶⁵ Genetic testing might also identify people needing particularly low or high doses of medications,⁶⁶ people more likely to attain remissions,^{67,68} or even people more likely to respond to a certain medication mechanism of action.⁶⁹ Identification of individual genetic or molecular factors, in the future, may help establish diagnoses in people with subsyndromal symptoms or unclear diagnoses, as well as further inform asymptomatic relatives of people with mental illnesses in making reproductive decisions and personal lifestyle choices.⁷⁰

At the same time, information of this type might also create social and psychological risks and pessimism in regard to the effectiveness of treatments.⁷¹ Potential adverse consequences could affect emotional well-being, family relationships, employment, and insurance.^{72,73} Thus, the potential of psychiatric genomics has fueled ongoing ethical and legal debates.^{74,75}

The availability of such complex information needs to be paired with a structured system of communicating the benefits and the risks of testing to patients to allow its effective incorporation into the process of shared medical decision making. In other areas of medicine, studies of communication of genetic information to patients have identified the importance of education, risk communication, and emotional support.⁷⁶⁻⁷⁸

Genetic information dramatically increases the complexity of risk. In cancer genetics, Huiart et al⁷⁹ outlined the difference between the individual risk of inheriting or transmitting predisposing genes and the individual risk of developing the disease. This is highly relevant for mental health, as most neuropsychiatric disorders are polygenic, and any single gene variation may have minimal impact on individual risk. Gene variations can have additive effects on the expression of a phenotype,⁸⁰ or a certain gene variation might be expressed only through interaction with the environment.⁸¹ The ability of a test to identify gene variation might be different from its ability to identify the phenotype of interest. Furthermore, for example in cytochrome system testing, identifying a certain phenotype, such as slow metabolizers, may or may not have clinical utility, depending on other factors, such as ethnicity or the medication choice involved.⁶⁶

As in other areas of medicine, communicating the meanings of uncertainty, risk, and statistics in mental health conditions is difficult.⁸² Patient education needs to include not only information about choices but also information to enhance statistical literacy. Several research findings have helped this field. For example, using absolute risks rather than relative risks and transforming probabilities into natural frequencies displayed as pictograms facilitate communication and understanding.^{83,84}

Specialized genetic counselors have traditionally provided risk information in medical genetics. More recently, decision aids focused on risk communication and patient education have become prominent.^{77,85} A recent review of risk communication interventions found that decision aids improved knowledge, but did not nec-

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essarily decrease anxiety.⁷⁷ Availability of decision aids prior to the encounter with a clinician did, however, increase time for discussion of personal risk rather than education.⁸⁶

Individual counseling has been identified as an important element of genetic communication to improve risk perception and to address the psychological and social effects of genetic testing on the patient and the family.^{71,77,87,88} Inaccurate perceptions of risk after communication were associated with the psychological health of the individual.⁷⁹ One-on-one counseling was associated with reduced decision conflict in general medicine,⁸⁹ but research on counseling related to genetic risk in mental health has not yet been done. Joint psychiatrist-genetic counselor consultation and family-based approaches have been proposed in mental health.⁹⁰

Psychiatrists, as well as other medical providers, score low on scales of patient involvement in decision making,⁹¹ perhaps in part because traditional genetic counseling has been based on autonomous choice models.⁹² Increased patient activation was described when mental health patients' own strategies for well-being and recovery were identified and supported.¹⁵ In general, patients expect and prefer help with decision making in studies of genetic information communication.^{78,93}

Shared decision making in mental health will need to incorporate, in the future, effective communication regarding genetic and molecular testing. Structured assessments prior to the consultation will facilitate expression of the patient's goals and values, including goals for genetic testing. Decision aids provided prior to the consultation could increase patients' knowledge and individualize information. The encounter with a provider should facilitate risk communication and decision making.

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Limitations

The barriers to shared decision making are legion.⁹⁴ Clinicians lack familiarity and training, sometimes disagree with the concept, and often have concerns regarding decisional capacity and legal responsibility. Patients often lack the information, empowerment, motivation, and self-efficacy needed to participate in shared decision making. Mental health systems almost universally lack the needed computer infrastructure. At a basic science level, concerns involve communicating uncertainty and risk, biases in many decision aids, and human biases in decision making in general.^{95,96} For example, mental health patients, like others, are biased by optimism regarding their own health, are confused by too many choices, have difficulties understanding statistical risks, and are influenced by biased information from industry. These issues need to be clarified by further research and addressed at many levels: basic decision-making science, clinician training, structural implementation, electronic infrastructure, patient empowerment, and so forth.

Summary and conclusions

Implementing shared decision making in routine mental health care offers considerable promise in terms of ethics, quality, informed decisions, patient satisfaction, enhanced ability for self-management, improved adherence, and meaningful outcomes. Putting these potentialities into everyday practice will be fraught with difficulties. Now is the time to address these barriers through research on shared decision making, as the information explosion and personalized medicine will require new educational structures, communication patterns, and decision-making forms. □

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La toma de decisiones compartidas en salud mental: perspectivas para la medicina personalizada

Este artículo describe el modelo de la toma de decisiones compartidas, revisa su situación actual en el campo de la salud mental y discute su potencial impacto en la medicina personalizada. La toma de decisiones compartidas traduce un proceso estructurado que fomenta la participación total del paciente y del proveedor. La investigación actual muestra que la toma de decisiones compartidas puede mejorar la participación de los pacientes mentales y la calidad de las decisiones en términos del conocimiento y los valores. Se debe estudiar el impacto de la toma de decisiones compartidas en la adherencia, el auto manejo de la enfermedad y las consecuencias en la salud. La implementación de la toma de decisiones compartidas en líneas generales requerirá de una reingeniería del circuito de la atención clínica en los ambientes de práctica cotidiana y un mayor empleo de la tecnología de la información. Se necesitarán cambios similares para combinar datos genómicos y otros datos biológicos con los valores y preferencias de los pacientes, y con la experiencia de los clínicos. El futuro de la medicina personalizada está claramente relacionado con nuestra capacidad de crear la infraestructura y la receptividad cultural a estos cambios.

Prise de décision partagée en santé mentale : en quête d'une médecine personnalisée

Cet article décrit le modèle de prise de décision partagée, le resitue dans le cadre actuel de la santé mentale et analyse son influence potentielle dans la médecine personnalisée. La prise de décision partagée est un processus structuré qui encourage la participation entière du patient et du médecin. La recherche actuelle montre que cette prise de décision peut favoriser la participation des patients psychiatriques et la qualité des décisions en termes de connaissances et de valeurs. Il faut en étudier l'influence sur l'adhésion au traitement, la prise en charge individuelle de la maladie par le patient et l'évolution deson'état de santé. La mise en œuvre étendue de cette prise de décision partagée nécessitera de réorganiser les soins cliniques dans le cadre d'une pratique de routine et d'utiliser de manière plus importante les technologies de l'information. Associer la génomique et les autres données biologiques avec les préférences des patients et l'expérience des médecins demandera également des changements. L'avenir de la médecine personnalisée dépend clairement de notre capacité à créer l'infrastructure et la réceptivité culturelle à ces changements.

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