

Shared Decision Making and Medication Management in the Recovery Process

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Mental health professionals commonly conceptualize medication management for people with severe mental illness in terms of strategies to increase compliance or adherence. The authors argue that compliance is an inadequate construct because it fails to capture the dynamic complexity of autonomous clients who must navigate decisional conflicts in learning to manage disorders over the course of years or decades. Compliance is rooted in medical paternalism and is at odds with principles of person-centered care and evidence-based medicine. Using medication is an active process that involves complex decision making and a chance to work through decisional conflicts. It requires a partnership between two experts: the client and the practitioner. Shared decision making provides a model for them to assess a treatment's advantages and disadvantages within the context of recovering a life after a diagnosis of a major mental disorder. (*Psychiatric Services* 57: 1636–1639, 2006)

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Although the exact definitions of compliance and noncompliance remain a topic of debate, Weiden and Rao (1) suggested that the most common definition of the word is “a deviation or cessation of a medication regimen that is less than what was recommended by the doctor.” Compliance interventions are often designed to increase clients’ behavioral conformity to a practitioner’s view of optimal treatment. Shared decision making diverges radically from compliance because it assumes that two experts—the client and the practitioner—must share their respective information and determine collaboratively the optimal treatment. Contemporary evidence-based approaches to the management of long-term medical illnesses are based on the process of shared decision making. Similarly high standards should be adopted in psychiatry. In this Open Forum, we present a rationale for adoption of the shared decision-making approach in psychiatry from both the client and practitioner points of view.

The client's perspective

Choice, self-determination, and empowerment are foundational values for people with disabilities, including people with psychiatric disabilities (2). Shared decision making is a clinical model that upholds these values. It helps to bridge the empirical evidence base, which is established on population averages, with the unique concerns, values, and life context of the individual client. From the vantage point of the individual health

care client, the efficacy of a particular medication is not certain. Instead, when a person is handed a prescription for medication, the question of how the medication will affect the individual becomes an open experiment for two co-investigators—the client and the practitioner.

Using medications is a dynamic journey, not a static event, particularly for people with long-term disorders (3). Researchers have noted that many clients approach medications like naïve scientists conducting a lay assessment of medication effects—not just on symptoms but on personal identity and quality of life as well (4). In this respect, people with psychiatric disabilities are very similar to other groups of people with long-term disorders. As with people who are HIV positive and using antiretroviral treatment, people with psychiatric disabilities sometimes assess that the treatment is worse than the disorder and reject or alter treatment accordingly (5). As with people who have rheumatoid arthritis, people with psychiatric disabilities sometimes assess that medications work best when used strategically to deal with certain symptoms or only when the symptoms are present and are experienced as distressing (6,7). As with people who are HIV positive, people with psychiatric disabilities sometimes assess that it is not worth using medications because of the discrimination and social rejection associated with medication use (3,8). As with cancer patients, people with psychiatric disabilities sometimes reject medications because they are an un-

wanted reminder of illness (9,10). As with people who have hypertension, people with psychiatric disabilities sometimes do not see the necessity of using medications because they are uncertain that they are actually ill (11). Finally, as with many people with long-term disorders, people with psychiatric disabilities sometimes conclude that it is best not to use medications as prescribed because they are ineffective (12).

The compliance model, with its emphasis on obedience to medical authority, is far too simplistic to address the complex decision-making processes that are required to discover optimal use of medications within the process of recovering from major mental disorders. For instance, Deegan (13) found that people with psychiatric disabilities often use "personal medicines," defined as self-initiated, nonpharmaceutical strategies, to improve wellness and avoid unwanted outcomes, such as hospitalization. Personal medicine includes activities and interventions that give life meaning and purpose, that raise self-esteem, and that promote a sense of mastery and accomplishment. When medications support or enable people to more effectively pursue activities such as employment, parenting, and returning to school, they are perceived by clients as a valued tool in the recovery process. However, if medications interfere with personal medicine, such that clients cannot engage in valued social roles and activities, the medications are viewed as blocking the recovery process and are often rejected. Insistence on compliance in such situations is experienced as countertherapeutic and unhelpful. On the other hand, shared decision making allows the practitioner to work as an expert collaborator, actively helping the client to identify personal medicines and to optimize regimens and dosages of specific medications to support and complement the recovery of valued social roles.

Sometimes there can be tension between the practitioner's and client's views of medication effects. Deegan (13) described this as a clash of perspectives and questioned who has the privilege to judge that a medication is "working." For example, a practition-

er might perceive that the medication is helping the client to be more in control, but the client might feel that "the medication is controlling me." The practitioner might observe that medication has returned the client to baseline, but the client might experience feeling that "I am not myself anymore." The practitioner might conclude that symptom abatement has been achieved, but the client might experience that the price of symptom abatement has been a disabling transformation of self into a "drugged me" or a "not-me." The compliance model fails to provide a framework for respectfully resolving such differences in perspective. The result is often an awkward and unhelpful standoff, in which the practitioner insists on compliance and the client quietly discontinues medications. Shared decision making, on the other hand, acknowledges two kinds of expertise and requires the two experts to explicitly establish consensus on what the problem is, what the treatment goals are, and how they will know when the goals have been met.

The practitioner's perspective

Psychiatric practitioners understand that current medications can be efficacious in terms of ameliorating the symptoms of severe mental illness and preventing relapses (14). They also recognize that nonadherence among mental health clients who are given these prescriptions is high, usually 50 percent or greater (15). The discrepancy between the established efficacy of medications and the significant number of clients who do not use them as prescribed can be frustrating for the clinician (16) and has historically been attributed to a failure on the part of clients to follow treatment as prescribed by the practitioner (17).

This construction of compliance as the client's failure to obey medical advice has been criticized along a number of dimensions over the past three decades: it is rooted in medical paternalism (3,18), it lacks an appreciation of the importance of the client's role in health care decisions (19), and it attributes deviance or blame to clients who do not follow medical advice (6). Additionally, it has been noted that in an era

of rapidly evolving scientific knowledge, the evidence base supporting and opposing treatment options is complex and at times contradictory or unclear (20). Thus the very ethics of practitioners who make decisions for clients and expect them to comply has been called into question (21).

Intuitively, practitioners have long understood that more than an insistence on compliance is required to help clients use medications effectively. Thus, in the midst of the enormous body of research literature on compliance and interventions to improve it, there has always been the call to move beyond compliance to therapeutic alliance. As early as 1957, Balint (22) contrasted patient-centered medicine with illness-centered care, effectively challenging medical paternalism by moving the client from the periphery to the center of medical decision making. In psychiatry, as early as the 1970s a negotiated approach to medication management was proposed as a two-stage process of forming a clinical hypothesis and negotiating a mutually acceptable treatment disposition between the client and practitioner (23). In the 1980s Diamond (24) suggested that clients' medication use sometimes reflected a desire to have control over their lives and outlined strategies for practitioners to establish a therapeutic alliance, including framing medication use in the context of the client's life, goals, and history. In the 1990s Frank and Gunderson (25) found a superior treatment course and outcome for clients who had good therapeutic alliances with practitioners. Corrigan and colleagues (26) proposed reframing compliance as a collaborative relationship in which both parties assume responsibility for creating a treatment regimen that will actually be carried out. Frank and colleagues (27) described a philosophy of outpatient care that included efforts to share information with clients over time and to present the treatment experience as an experiment in which the client and the clinician are coinvestigators with complementary areas of expertise. Aquila and colleagues (28) proposed that the therapeutic alliance be reframed as a rehabilitation alliance involving a sup-

portive network of care, including the practitioner, client, family members, friends, and other caregivers.

In the 21st century, the medical paternalism in which the construct of compliance is rooted was further challenged by the *Crossing the Quality Chasm* report by the Institute of Medicine (29). In that report, person-centered care was cited as one of six overarching aims to achieve quality in medicine and was characterized as being “responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The 2006 follow-up report (30) found that the framework of the Quality Chasm report was applicable to providing health care for people with substance abuse or mental health conditions, despite some unique challenges posed by these populations. That report again called for care to be person centered and supportive of the decision-making abilities and preferences for treatment and recovery of people with substance use or mental health conditions.

The inexorable trend is away from compliance and toward shared decision making, which entails a process of collaboration to arrive at a mutually acceptable plan for moving forward in the treatment process. This method involves two experts: one who knows the scientific literature and has clinical experience, and one who knows his or her own preferences and subjective experiences. The practitioner’s role is not to ensure compliance but rather to help the client learn to use medications and other coping strategies, optimally in the process of learning to manage his or her own illness. Shared decision making requires the type of therapeutic relationship needed to help the client manage co-occurring substance abuse, to avoid or minimize medication side effects, and to develop practical solutions to using medications in ways that support recovery. In the shared decision-making paradigm, the language of medical authority, compliance with therapy, and coercive treatments disappears in favor of terms and concepts like education, working alliance, individual experience, informed choice, collaborative

experiments, and self-management of illness.

There are undoubtedly situations in which shared decision making is not fully applicable. For instance, in emergency situations or in situations in which there is temporary decisional incapacity, shared decision making may not be achievable. In such situations, psychiatric advance directives can help protect client autonomy and provide practitioners with a guide to making treatment decisions that are guided by clients’ preferences and values. Advance directives are a method of treatment planning consistent with client-centered care and shared decision making. They have been shown to be of substantial interest to clients who are high users of crisis and hospital services, especially if practitioners are supportive of their use (31).

Future directions

Research on shared decision making in psychiatry is under way (32–34), but much more is needed. We need to better understand the dynamic nature of decisional conflict experienced by people with psychiatric disabilities over the course of the disorder and recovery. Rigorous qualitative studies are particularly helpful in mapping the phenomenology of such complex processes (3,35–37). We need to develop and study tools that support the shared decision-making process. Specifically, up-to-date, Internet-based decision support aids must be developed so that practitioners can quickly access relevant research findings (38). Clients also require accessible information and decision aids in order to make decisions about treatment options in light of personal life goals, values, and experience (39). Additional interventions are needed to support clients’ movement through decisional conflict, to help activate clients to become involved in the shared decision-making process, and to train practitioners in communicating and collaborating with clients (40). Support for clients who are working through decisional conflict should be multidimensional and coordinated across service types and settings. Complementary components for self-help, peer-to-peer

support, case management services, and medical teams should be developed in settings that include mental health clinics, hospitals, and primary medical care. The effectiveness of these supports and interventions, as well as related cost savings, should also be researched.

Conclusions

Using medication is an active process that involves complex decision making and a chance to work through decisional conflicts. It requires a partnership between two experts: the client and the practitioner. Shared decision making embraces current science, individual experiences, the client’s right to autonomy, informed decision making, the practitioner’s expertise, and the dyad’s skill in forming an alliance. It provides a model for practitioners and clients during the dynamic process of assessing a treatment’s advantages and disadvantages within the context of recovering a life after a diagnosis of a major mental disorder.

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