

Noncompliance, Nonadherence, and Dropout: Outmoded Terms for Modern Recovery-Oriented Mental Health

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Discontinuing mental health treatment is traditionally viewed as an adverse event. In this Open Forum the authors explore underlying assumptions that inform this view and encourage reconsideration of the event as a personal choice

and of the common tendency to describe people who discontinue treatment as “dropouts.”

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When people with a serious mental illness refuse to follow through with their care provider's recommended course of treatment, concerns often are raised, perhaps most prominently in clinical settings but often also by family members and even more generally by the popular media and the public. Discontinuing psychiatric medication, resisting psychiatric care, ceasing treatment against medical advice, not attending a social skills group, and disengaging from services are often disparaged as acts of “noncompliance” or “nonadherence” by “dropouts.” The assumption is that these actions inevitably lead to poor outcomes.

But not following up on or discontinuing recommended care, which is quite common across medicine, may be the product of various processes, ranging from active decision making to reach an informed choice to a lack of decision making altogether because of predominant negative symptoms. The way mental health professionals currently interpret the act of not using or discontinuing treatment is influenced by several underlying assumptions that we would like to make explicit. We challenge the presumed universality of these terms and reconsider whether discontinuing treatment should be referred to as “noncompliance” or “nonadherence” and whether those taking such action should be described as “dropouts.”

First, there is the core assumption that psychiatric treatments are always beneficial to those receiving them. If this were indeed the case, the use of such treatments should be supported and disengagement from them could be viewed as universally negative. This assumption, however, should be challenged. For example, recent studies suggest that for some people the discontinuation of antipsychotic medications can, at times, lead to better outcomes than continued long-term use (1,2).

Second, an additional core assumption is that persons with serious mental illness will need treatment for the remainder of their lives, because their conditions are conceptualized as chronic if not also progressive. This assumption also may be challenged by the over 40 years of longitudinal research that suggests that most people will experience improvement in their condition over time, many recovering fully, even from an illness as presumably severe as schizophrenia (3–6).

Third, there is a tendency to simplify the complexity of treatment choices by exaggerating and overemphasizing the actual or potential benefits while minimizing or ignoring the risks. For example, even assertive community treatment (ACT)—which has been widely adopted because it has been found to improve the desired outcomes of community tenure and reduced hospitalizations—is not without its own “side effects.” Controlled research has shown that people who received ACT, in addition to having improved outcomes on some domains, had increased symptoms and lower social functioning compared with people who did not receive ACT (7).

Fourth is the assumption that practitioners invariably know better than the persons with mental illnesses what the best treatments are, resulting in the view that refusing recommended treatment is necessarily the “wrong” choice. Furthermore, in the case of psychiatric illness (as opposed to more traditionally understood physical illnesses, for which nonadherence rates can be equally high), choosing not to continue treatment might be labeled not only as a wrong choice but also as evidence of lacking the ability to make choices at all due to poor judgment, low insight, or reasoning impaired by the illness itself (8). So in case a psychiatric label is not stigmatizing enough, one can easily become susceptible to

other stigmatizing labels such as *noncompliant*, *nonadherent*, or as a *dropout* by virtue of the simple lack of follow-through with recommended treatment.

We are not claiming that a mental health provider must agree with or support every health care decision made by his or her clients, nor are we arguing that all decisions are necessarily rational, constructive, or beneficial. Clearly, many health care decisions are far from that. What we are stating is that there are clinical and legal means to assess and deal with those rare and extreme cases in which decision making is, at least temporarily, impaired for any range of reasons, including by the symptoms of a mental illness. We need not confuse those cases, however, with the majority of everyday health care decisions nor let their dramatic or occasionally traumatic nature be used to dismiss or overturn health care decisions that differ from recommended treatments.

The argument we are making is that every life choice, and certainly every treatment choice, has a broad range of potential advantages as well as dangers. An experienced clinician, as wise and well intentioned as he or she might be, can never really understand the viewpoint of the person who must weigh these consequences within the context of his or her daily life, values, and preferences in the making of autonomous decisions. Having a serious mental illness should not deprive persons from exercising this fundamental and highly valued aspect of our humanity, which is taking responsibility for our own decisions in health and in life.

Both the research cited above as well as guiding principles of recovery-oriented care suggest that individuals with mental illnesses who do not use recommended treatment are not simply making the “wrong” choice or lacking the ability to make choices of their own. There is a broad range of reasons why people with a serious mental illness are not receiving treatment. Some may not be receiving treatment because of formidable barriers to access. Clearly a major public health concern is the many people with mental illness who need, want, and could benefit from treatment but have no access to it. Others may have received treatment but stopped because of a range of negative experiences with the treatment itself (such as medication side effects) or its service delivery (settings or interactions that were experienced as toxic). Still others may have had less negative treatment experiences and stopped because they felt little in their lives had changed as a result of care, so continuing treatment did not seem worth their time and effort. On the other hand, it is possible that for some people, the care they received was viewed as positive—so positive and effective, in fact, that they no longer felt they needed it (9). Some may want to solve their problems and cope with their symptoms on their own (10) or replace the prescribed medication for “personal medicine” (11), or they may experience ambivalence toward symptoms such as hallucinated voices, missing them when they are gone (12), and still others may have a nonmedical framework for their experiences (13) in which case treatment is perceived and experienced by them as irrelevant.

Discontinuing treatment can happen for a broad array of reasons, and this should be of no surprise considering the range of available treatments in various settings used by an enormously heterogeneous group of people. As in other branches of medicine, in mental health, each person should be able to make his or her own informed cost-benefit calculations about the effects, side effects, and other costs of treatment and the effects, side effects, and other costs of discontinuing treatment. Clinicians are often fast to label discontinuing treatment as a bad choice often generated by or a sign of illness rather than as a decision based on considerations of which we are simply unaware. To provide only one of many possible examples, young men whose antipsychotic medication renders them sexually impotent may choose sexual performance and satisfaction—along with a sense of their own masculinity—over reduced symptoms but may be reluctant to share these deliberations with others.

There are implications to taking a more nuanced and informed perspective on decisions to use or not use psychiatric treatment. The first is to realize that treatment choices are extremely complex and involve numerous dynamic factors that can lead to a variety of choices (14). Second, our goal should be to understand and learn from these choices rather than be quick to use value-laden terms such as *noncompliance*, *nonadherence*, or *dropout* to describe them. Third, talk about person-centered care needs to be translated into practice through a commitment to personal rather than collective goals. For most, the process of exploring, identifying, and trying to make progress toward personal goals requires the context of stable, reliable, and continuously supportive relationships, which are becoming rare in most systems of care. Fourth, we should learn to support these choices and help patients monitor the degree to which they perceive them as helpful over time, strengthening the therapeutic alliance so that patients will feel free to consult with us as needed. This might help inform us about a broader range of personal recovery paths people choose, which mental health professionals currently know little about. People do not share these alternative strategies with us, and they fall outside of the scope of our attention.

By carefully listening to people who choose not to initiate or continue with treatment, we might find out what those considerations are. For example, we might learn what they are looking for from services or life beyond services, what obstacles they face in adhering to treatment, and how what we are offering may fall short or miss the mark. In doing so, we might learn that some people not only actively choose to discontinue treatment but consider this choice an important part of their own recovery process.

Shifting the focus from compliance to self-determination (15,16) is perhaps best manifested in the current interest in shared decision making (SDM), which emphasizes information exchange, deliberation, and an agreed decision (17). A recently updated review (Zisman-Ilani Y, Barnett E, Harik J, et al., manuscript submitted, 2017) shows that SDM

interventions in mental health care, focused primarily on medication use, have been successfully implemented in routine care, demonstrating an increase in consumer knowledge, involvement, and satisfaction. A recent study of the SDM experiences of people with serious mental illness (18) showed that the strongest barrier to participating in the decision-making process was the struggle to be perceived as competent and equal to their providers. In addition, it has been shown that when people are matched to their treatment preference they are more likely to adhere to their treatment choice and have better treatment outcomes (19,20).

Finally, changing our own perception of the meaning of not following up on or discontinuing recommended care opens a new vista for research, including studies of how people manage to live with, and at times recover from, mental illnesses outside of formal treatment options (21). Another vista seldom considered is how such people may reject even the most recovery-oriented of services for implying that patients are expected to do more, be further along in recovery, or be “better” than they already are. In this case, there may be continued confusion between mental illnesses and moral failings, with people equating the “need” for treatment with a perceived need for self-betterment or self-improvement. The counter to such a stigmatized and stigmatizing view of mental illness may well require fostering a sense of acceptance of who one is as a person, irrespective of refractory symptoms. Achieving this kind of self-acceptance and sense of self-worth has ordinarily been promoted through different forms of religion and psychotherapy but can be promoted more broadly by mental health services in general. In this case, terminating treatment should not be viewed as “dropping out,” but may instead be encouraged as a primary reflection of the person’s underlying humanity.

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