IN THEIR OWN WORDS

Patients Personify What Ethical Principles Mean

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Reflection on human experience is invaluable in understanding the meaning of ethical principles within the lives of people. Such reflection may help us to identify, for example, what actually helps people to flourish or how people are willing to balance concern for their autonomy with concern for their safety.

To that end, I will use some patients' words to help explore the ethics of mental health care for individuals with severe mental illnesses such as major depression, bipolar disorder, schizophrenia and post-traumatic stress disorder. These are disorders that often involve significant impairments — distress, suffering, and a compromised ability to carry out the tasks of daily living.

The quotations that follow are from a dozen individuals who wrote about their experiences of being hospitalized for psychiatric problems. Their stories were published as part of a narrative symposium in the journal *Narrative Inquiry in Bioethics*,[1,2] and I have tried to draw out themes and corresponding lessons relevant to inpatient and outpatient care of people with severe mental illnesses, particularly when they are in acute phases.

FEAR AND DIGNITY

Mental illness can be experienced as a loss of control in many areas — control over one's own thoughts and decisions, control to leave a facility or control to consent to treatments. The patients who shared stories about their hospitalization experiences communicated a profound sense of vulnerability when they suffered psychosis, blackouts or severe depression.

Many were afraid. When an individual doesn't understand the causes of psychological impairments and he or she is offered no hope of recovery, fear is compounded by the thought of permanence or that death is the only escape.

Patients often expressed a fear of hurting themselves or others. Several experienced a profound fear that others would hurt them. Sometimes this fear arose from stereotypes about psychiatric facilities and the inability to protect oneself when heavily medicated or confined. Sometimes the fear arose from past experiences of physical or sexual abuse. Re-establishing a basic sense of safety was so important that some patients were willing to sacrifice their liberties within a locked psychiatric unit.

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One patient wrote:

I knew I needed help; the hospital represented a possibility to finally get it. But a mental patient is also disenfranchised and isolated by definition — away from the world, I was totally vulnerable.

Another said:

When I was 12, I appreciated my need to be locked up. I was aware of the threat I posed to myself. I accepted that a certain amount of my autonomy needed to be sacrificed for my own safety.

However, when facilities or treating psychiatrists restricted their liberties more than necessary — for example, by confiscating all of their belongings, limiting phone calls and visitors, using restraints or confining them to the indoors — patients regarded it as an affront to their dignity. Also, many wrote about stigma, and one person poignantly related the concept of stigma to the concept of dignity:

Stigma is ignorance of what is true and real ... I exist in my own right, as a person, my own person beyond my illness and I have my own experience that doesn't fit into a nicely wrapped box with a clinical name and cause.

Ironically, patients themselves sometimes had a negative perception of people with severe mental illnesses, particularly before they got to know other patients. For example, one wrote:

I felt like I was in jail and I was scared. I didn't want to be there with all those "wackos."

According to the patients' stories, nothing created a sense of safety as much as individual acts of kindness by health care providers or peers. For example, one noted:

I treasured those occasions when our encounters and communications transcended our roles and we related to each other as people aware of our shared humanity.

A man who suffered from severe PTSD related:

Hatred was pouring into my face like blood. I had never been so angry. I called for an ambulance, stating that I was homicidal

and suicidal. ... I was put into a bed with restraints and taken up to the unit. ... a gentle nurse approach me and smiled warmly saying, "How are you feeling Mr. [Name]?" He could tell by my facial expression that I was feeling inordinately angry, but he gave me only salvation: He treated me as he would have wished to be treated. This act of virtue calmed me and helped me to realize I was truly in the right place.

Kindness is always a virtue among caregivers. But it appears to have unique value when patients are vulnerable and stigmatized.

This makes sense. Human beings have a history of treating terribly those they label as unlike themselves.[3] When we reassure patients who are vulnerable and stigmatized that we empathize, that we view them as like ourselves, we inspire confidence that we will do our best to help them.

NEED FOR EVIDENCE-BASED TREATMENTS

There is a perception about mental health care that current diagnostic approaches lack rigorous scientific validity and that many severe mental illnesses lack effective treatments.[4] From a patient's point of view, this perception is particularly understandable.

Here is what one — only one — patient wrote about treatment that seemed nearly ideal.

The providers' choice in medications was always the correct choice. Their assessment and the manner they used to approach me had to play a role in this process. They also did not overmedicate me, but found just the right dosage that would calm my symptoms, but would not cause bad side-effects.

Most wrote about experiences with medications that weren't so positive. Psychotropic medicines can help reduce symptoms and even save lives; for example, lithium has been demonstrated in many studies to manage symptoms of bipolar disorder and to significantly reduce rates of suicide.[5] But it is well known that psychotropic medications may have undesirable side effects and that a patient's symptoms may persist despite medical treatment. What surprised some was how difficult it was to find an appropriate prescription:

During the nine days I was in the private hospital, I was on Seroquel, Depakote, Zyprexa, and then for the three-week day-program after hospitalization, Geodon. Who really knows the impact of stopping and starting these powerful medications in such a short time frame, with no careful weaning off before starting a new one? I was not strong enough or well enough to "just say no."

Another said his psychiatrist's recommendation *… was to continue trying antidepressants, six weeks per prescription. 'You may have to try five or six drugs before you find one that works.'*

Trial-and-error prescribing does not instill confidence, but it is not necessarily a sign of the prescriber's incompetence. Instead, it is a symptom of the state of psychiatric science today. The uncertainty surrounding treatment plans derives in part from the uncertainty surrounding psychiatric diagnosis, which also was a theme among the patients. As one said:

Regarding diagnoses, I'd like to add that I received a multitude of them, some of which seemed conflicting and confusing. I took all of them to heart, however, and looked deeply into what was true for me, and looked for where I needed to make corrections. I still struggle with overcoming external and internal stigmas everyday.

However, once it is made, a diagnosis may affect a patient's self-image, not to mention employability and insurance rates. A patient recalled:

My next move was to ask what was wrong with me. This was one of the biggest mistakes of my life, to ask this question. From this point forward, my experience had a label.

The National Institute of Mental Health recently has required that most of the research it supports adopt a Research Domain Criteria (RDoC) framework. The RDoC framework focuses less on diagnoses and more on narrowly defined impairments that are of clinical importance, and it requires examination of both psychological and biological factors using validated measures.[6] The goal is for the RDoC framework to yield discoveries that may transform psychiatric diagnosis and treatment, enabling the field of psychiatry to enjoy the same level of advancement that, say, pediatric cancer treatment has seen in recent decades.

Research with individuals who have severe mental illnesses can be challenging. Questions arise about the ability to obtain informed consent when individuals are experiencing psychological impairments. However, there are validated tests for assessing the decisional capacity of participants in mental health trials, as well as evidence-based approaches to enhancing the consent process.[7]

Similarly, there are strategies that have been used successfully to manage risk even in studies that involve placebo controls or that require discontinuation of medication prior to starting an experimental drug.[8] A team of experts funded by the NIMH has argued that the oversight of psychiatric research in recent decades has shifted so far toward protection of participants that it ignores regulatory and ethical obligations to foster participant autonomy and to conduct research that benefits populations in need of medical innovations.[9]

CARING FOR THE WHOLE PERSON

It often has been observed that our generation cannot handle silence and stillness. We may feel our sanity depends upon the distractions provided by cell phones, social media or television. Ironically, when people are hospitalized for a severe mental illness, it is not unusual that their phones are confiscated, their access to social media is removed and, when particularly agitated, they are isolated.

Sometimes there are good reasons for this. Nevertheless, silence and isolation can serve to reinforce a powerful tendency to look inward — to ruminate on negative thoughts or to dwell on depressed affect. Viktor Frankl, a psychiatrist and survivor of Nazi concentration camps, developed a model of psychotherapy that recognized the value of self-transcendence. To be clear, self-transcendence for Frankl generally meant much more than distraction; it meant engaging a positive meaning in life or another person. But at times, simple distraction from a feared symptom can be therapeutic.[10]

The patients appeared to share this perspec-

tive. Occupational therapy programs got particularly high marks within the context of inpatient care. A patient said:

I remember one particular occupational therapist who would offer many activities and fun projects, like artwork or crafts. I was allowed to choose the activity I felt would best bolster my self-confidence, take my mind off of my problems and establish my self-awareness.

Another wrote:

My other savior was the use of the occupational therapy room, where there were three computers connected to the internet and the usage of the arts and crafts supplies. I was in the OT room every chance I could get.

The impairments that individuals experience when a mental illness is acute often contribute to other problems that endure even after the impairments subside. Severe depression, mania and psychosis commonly contribute to unemployment, which in turn contributes to poverty and homelessness. Thus, even when medical treatment is deemed a success and symptoms diminish, patients often have basic needs that must be met not only to survive, but to protect their mental well-being. This need for basic resources was addressed several times. A patient wrote:

I was desperate and anxious. I was going into debt because I had no job. I had no car, and it was difficult for me to get around. I felt such shame ... I was homeless for six months.

Another patient said, *I had just lost my only source of income... I would get cut off [in group therapy] because I was talking about having to go bankrupt, losing my home, my car, etc. For some reason, they didn't want me to talk about it. I asked why, and they told me it was because they can't help people with financial issues. I told them that it was the reason I was feeling unsafe, and it was like they just didn't care.*

These observations point to the need for social work support, careful discharge planning and a social safety net. They also point to the need for advocacy: Social workers cannot discharge patients to safe housing or arrange for transportation to a workplace when none is available.

CONCLUSIONS

Caring for individuals with severe mental illnesses is challenging. The evidence base supporting specific diagnoses and treatment plans is imperfect, patient compliance with treatment plans is often low for a variety of reasons, and protecting patients sometimes requires the use of medications or involuntary treatment. The well-being of patients often is influenced strongly by socio-economic factors such as joblessness that may be tied to the disorder itself but are largely beyond the control of care providers.

Despite the challenges, care providers have tremendous opportunities to help those who are suffering from severe mental illnesses. As the patients wrote, performing small acts of kindness, communicating with people respectfully and as adults, providing choice and liberty as much as possible, offering access to peer support systems and occupational therapy services, involving social workers to address basic needs for housing and transportation, and providing evidence-based therapy — all of these serve to help make patients feel safe, experience dignity and live a meaningful life.

At the same time, the modest evidence base for diagnosis and treatment in mental health care poses a serious problem. Health care institutions can advance the well-being of patients by facilitating the ethical conduct of mental health research.

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NOTES
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2. V. Barnard et al., "Personal Narratives: Experiences of Psychiatric Hospitalization," *Narrative Inquiry in Bioethics* 1, no. 1 (2011): 3-28.
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4. Michael J. Kozak and Bruce N. Cuthbert, "The NIMH Research Domain Criteria Initiative: Background, Issues, and Pragmatics," *Psychophysiology* 53, no. 3 (March 2016): 286-97.

5. Paul Grof and Bruno Müller-Oerlinghausen, "A Critical Appraisal of Lithium's Efficacy and Effectiveness: The Last 60 Years," *Bipolar Disorders* 11, s2 (June 2009): 10-19.

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8. Ana S. Iltis et al., "Addressing Risks to Advance Mental Health Research," *JAMA Psychiatry* 70, no. 12 (2013): 1363-71.

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