"Us" IS "Them:" Working with the Psychiatrically Labeled

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In this personal narrative, the author recounts his experiences with psychiatrically labeled adults that have increased his understanding of and appreciation for people beyond their labels, and have helped him to de-program his pathology-based training and understanding of mental illness. He also discusses the integration of some of these experiences into courses he teaches with graduate social work students.

Note
Case narratives have been modified so that privacy is respected and confidentiality maintained. This article is dedicated to the lives of people with severe and persisting mental illness, and to those who provide services to this population.

The Joy of Sex
Scott was 25, loved baseball, classic rock, and his car. He also was an amazing classical and jazz guitarist. When I first met him, I thought that Scott was a staff member of the community support program. He was dressed like other staff members – jeans, oxford shirt, deck shoes, and had a confident, self-assured manner to him. In fact, he was the first person to greet me at the door of the Tudor-style house and to give me a tour of the day treatment program. Scott was warm, friendly, and accommodating. I was interested, curious, and attentive. I had been told to look for “Scott” who would give me a tour of the facility.

“Great to meet you. I’ve been expecting you. Come on in. Would you like the petit or the grand tour?” Scott said.

“Well I’ve got time if you do, and I will be spending a lot of time here, so I’ll take the grand, if that’s all right,” I replied.

Scott ushered me along a short corridor. “This is the day activity room,” he said, his arm sweeping a large living room with several couches and chairs lining the walls and facing a large television along one wall. “As you can tell from the smoke and yellow walls, it is also the designated smoking area,” he chuckled. “There are a lot of smokers here. It sure makes it tough to quit.”

He continued along, giving me a brief yet very thorough history of the day treatment program as he went. “Yorke House was opened six years ago and was designed to provide support for folks recently discharged from a mental hospital. Many of the folks here have spent time in the state-operated psychiatric facilities. Some have been in and out for years; some are more recently diagnosed. We are a consumer-driven, low-barrier facility that emphasizes recovery from psychiatric illness and peer support. Services include case management, transitional housing, transitional employment, counseling, psycho-education, and psychiatric services.” He paused. “It’s a great place just to hang and socialize, too – you, know, a drop-in.” Scott had an ease that I appreciated. I looked forward to working with him as a colleague.

“Where is everybody now?” I asked. We had continued through the dining room and into the kitchen, which like the rest of the house was empty. The clubhouse was not at all the hub of activity that I had expected.

“On Tuesdays folks get driven to the mental health center for med checks and appointments,” he replied. “I’m just here
today to give you the tour and to meet with you.”

“Where’s your office?” I asked. “I was told that you were housed here.”

Scott looked at me confused, then embarrassed. “Oh, that’s the other Scott - Scott Patton. He’s running late and asked me to keep you busy until he arrived. I don’t work here, I’m a consumer.”

“Oh, I’m sorry. You’re the other Scott. I didn’t make the connection,” I stumbled. He paused as we continued out the back door onto the deck. He offered me a seat. The porch overlooked a sloping back yard bisected by a large vegetable garden distinguished by several rows of large cornstalks. It was late summer, and the heat was oppressive and humid.

“I’m doing pretty well, right now,” he continued. “I got out of the State hospital in April after three months. They say I have schizophrenia, though I don’t really know.” He paused. “I do know that I was at the community college, finals were coming up, I hadn’t slept for a while, and that it was a really stressful time.” He looked at me. “They wanted me to meet you, because you’re going to be helping me get into a transitional apartment.”

“Yes, you’re in line for an apartment as soon as we match you with a roommate. It should be ready before the fall semester. Will you be continuing college?” I asked.

“My case manager thinks that I should take a year off, but I really want to push through. I really feel fine now, except for the medication they have me on - makes me sleepy and screws me up in other ways.”

“What’s really important to me is that I have a roommate that likes music,” Scott stated. “It’s not loud or anything - classical and jazz - but I do like to play late at night at times.”

He continued on about his passion for music as I reflected on the information I recalled about Scott from his chart. I didn’t notice any overt signs of his illness as we completed our tour.

Scott and I worked together closely over the next several months. He got his apartment with a clubhouse friend, Steve, and continued community college in the fall and started to attend the clubhouse less and less frequently. He appeared to be doing great.

I received the call late on Friday night. It was a crisis team member. He’d received a call from a consumer neighbor of Scott’s who had been concerned about Scott and his increasing isolation. I was surprised. I’d not seen Scott in several weeks and had assumed that he had been caught up with school. I agreed to pay a visit first thing in the morning.

The first thing that struck me as I drove into the complex and glanced at Scott’s third floor window was the drawn shades. I parked and walked the two flights to his door, pausing briefly to listen before knocking. There was no answer, and I knocked more loudly. Muffled sounds approached the door, and I sensed myself being assessed through the peephole. A pause, then the door opened a crack, stopping at the end of its short chain.

“Yeah. What do you want?” Scott was curt.

“Scott it’s me, David. I hadn’t seen you in awhile and wanted to stop by to see how you were doing ....” I stepped back as the strong, foul stench of stale cigarette smoke wafted over me. “I tried calling several times, but there was no answer so I thought that I would just stop in.” I paused when Scott didn’t respond. “May we talk?” I asked.

Silence. Then the door closed, and I heard the chain being removed.

The change in Scott’s appearance was striking. His hair, once neat and clean, was now greasy and matted, cowlicks sticking this way and that. He clearly had not shaved in some time, and he wore a stained white t-shirt and jeans. The contact lenses were gone, and he had thick glasses on. He was barefoot and disheveled.
The transformation in the apartment was equally severe. It was stifling. Windows were closed, shades drawn, and despite the cool fall day outside, the temperature must have been 80. Stale cigarette odor permeated the apartment, intermingled with body odor and bad food. Several small plates on the coffee table serving as ashtrays were overflowing, and there were numerous burn marks in the new Crate and Barrel table. Dirty dishes were on the counter, in the sink, and on most tables. A few empty beer bottles, some half full with cigarette butts floating in them, were scattered about. A plastic trash container was tipped over in the dining room, its contents spilled over onto the floor.

I was momentarily speechless, unsure how to address Scott. He ushered me to the couch, tossing some newspapers to the floor to make room. Scott slouched in the chair kitty-corner to me, his legs crossed and his head resting on his chest.

I decided on a somewhat direct approach. “Scott, I’m actually here because folks were concerned about you. We haven’t seen you in quite some time at the clubhouse.” I paused, “I’m concerned about you... can you tell me how you’re doing?”

He said nothing. It was almost as if he didn’t hear me. I waited a moment and continued, leaning forward and speaking more softly. “Scott, what’s going on with you, right now? You seem so far away...”

Nothing. I sat quietly, pondering.

After a moment, Scott’s head raised and looked at me warily. Then he spoke, slowly and deliberately, his eyes still very far away.

“David... It’s been a while... how’s the apartment program?... It’s good to see you... I haven’t been to Yorke House... too much shit there. You know they worship the devil there? It’s in their eyes, the little flecks of yellow... cat eyes, the eyes of fire... that’s the sign of the devil... I can’t go there anymore, because I don’t have the yellow and they’ll know and they’ll kill me because I won’t breathe the fire...”

Scott leaned forward with slow deliberation, his eyes locking onto mine, searching, suspicious. His voice increased in volume and became more pressured and tense.

“You said they sent you. Have you come for me? I’m not coming.” He peered even more closely into my face. “You have yellow in your left eye. They almost have you now. You’re the messenger. I see the shit in you.” He looked haunted and challenging. I suddenly appeared to be a great threat to him.

In a moment, Scott had gone from looking almost catatonic to showing a fierce, focused intensity. His behavior was frightening me.

“Scott,” I said, with confidence I didn’t altogether feel, “I’m your friend, and I’m here only to offer my help to you.” I gambled. “Scott, look in my right eye, and you’ll see that I’m speaking the truth... I’m here to help...”

Scott stared at me, frightened. He looked to his left and responded to an unseen presence: “Okay, but I’m not going there.” Gradually the look of panic diminished and he seemed to relax a bit.

“They haven’t taken you yet,” Scott said. “They tried to lower my shield with the pills, to make me more receptive, but I fought it off and my eyes are blue. See, David?” He removed his glasses, leaned far forward, and using his thumb and fingers he pulled his eyes open wide like an owl for me to see.

“Scott, how long have you stopped taking your Melleril?”

“The pills?” he asked, wariness edging back into his voice. “Why do you care? Did they send you to check on me? The pills suck... I can’t get off. They’re no good while I’m in school.”

I calculated quickly — five weeks since the start of the semester. “Scott, I’m not going to ask you to come to Yorke House right now,
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but I would like you to see Dr. Mishra again. Maybe she can help come up with some other ideas about helping you. Are you still going to school?”

“Mishra was all right, but my teachers are all shit. I can’t go there. I’m not going to take any more pills, they’re shit.”

“Scott, I’d like to make an appointment for you to see Dr. Mishra. Would that be all right?” I rose and walked toward the window. “Do you mind if I open a window?”

“The smoke in here keeps out the smoke of hell. The devil won’t come here.” He looked wary again. “You want to bring in the smoke of hell. The yellow is back. You have to leave now.” He stood abruptly. “Tell everyone that I am fine. Thank them for their help, and tell them I don’t need any more help.”

I complied with Scott’s request and left, pondering his condition during the 15-minute ride back to the mental health center. This was my first experience with Scott in a psychotic episode and I was shaken by the transformation. Though he did not appear to be an imminent threat to himself or to others, his decompensation was frightening. But his psychosis was bizarre and appeared to include command hallucinations. He did not seem able to care safely for himself at the moment, as I recalled his active psychosis and the cigarette burns on the coffee table. I decided to consult with the crisis team and to request a psychiatric evaluation.

Scott was deemed a danger to himself and involuntarily hospitalized. He spent the next six months in the State psychiatric facility. Initially he refused all medications and his condition deteriorated rapidly and drastically. During one of my visits midway through his stay, I hardly recognized Scott. His hair was long and uncut, his fingernails uncut and curling over the tips of his yellowed fingers. He chain smoked “to keep away the smoke of hell.” The negative symptoms of his illness were now much more apparent. Scott exhibited a significant degree of alogia, or poverty of speech – his responses to my questions were empty and lacked any substance. He also was experiencing avolition to a milder degree; his hospital case manager reported that Scott appeared to have difficulty in initiating goal-directed activity and appeared lethargic and lifeless much of the time. The flattening of Scott’s affect was attributed more to the side effects of the antipsychotic medication that he ultimately agreed to take. Certain antipsychotic medications may produce extrapyramidal side effects, such as bradykinesia, that can mimic flattening of affect (DSM IV, 2000).

At the persistent urging of his sister, with whom he had a very close relationship, Scott eventually agreed to remain on a course of treatment that included anti-psychotic medication and within three months he was released again into the community. Months later Scott was able to explain to me the course of his decompensation.

“Really, what it came down to was sex,” he told me in a moment of self-reflection. “I met this wonderful girl in school, Lisa, and we really wanted to have sex.” He paused. “I hate Melleril because it screws up my ejaculation. It’s always been how I relax at night, you know, de-stress. With Melleril everything goes back up inside of me instead of coming out. Doc calls it retrograde ejaculation. It hurts like hell. Being with Lisa really pumped me up and she wanted to have sex, but I couldn’t. I couldn’t relieve myself and couldn’t have sex with Lisa. It really sucked, so I said fuck the pills. By the time I was ready to have sex, I was so screwed up in the head that I thought Lisa was the devil. We never did end up doing it.”

Medications have side effects that can be painful and distressing. In this case Scott, a young, healthy, and sexual man had been experiencing a very real side effect of the medication he was taking – sexual dysfunction. The desire was stronger than ever, particularly
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with a new girlfriend, but ejaculation was painful and distressing. Scott found himself in a quandary. He could remain on his antipsychotic and suffer painful sexual dysfunction or gamble with ceasing his medication and regaining his previous level of sexual functioning. The conflict was all the more pressing with the pressure in his new relationship to have sex. Over the years that I knew him, Scott tried various anti-psychotic medications, and while many did not have the sexual side effects that he so disliked, they also did not effectively control his psychosis. For Scott it came down to a choice between possible psychosis versus sexual pleasure and self-soothing; for him, the two appeared to be mutually exclusive. Eventually Scott chose to remain on a moderately effective medication that kept his delusions and most of the hallucinations under control, but had as a side effect mild flattening of affect; sexual dysfunction was not a side effect.

A Matter of Perspective

Sara was a 25-year-old woman who was a prime candidate for the supported living program. She was very high functioning; she was religious about taking her medication and very good about attending the day treatment program. She’d been living at home since leaving school at age 21. The voices had started during her junior year at college, and she had been hospitalized, diagnosed with schizophrenia, and was never able to return to college. She had been a Philosophy and English Literature double major, and during her first two years had maintained a 4.0 GPA. Her history indicated that when she decompensated, Sara experienced only the positive signs of her illness, meaning an excess or distortion of typical functions (DSM IV, 2000). In her case, this was manifested by bizarre delusions and visual and auditory hallucinations. She had none of the negative symptoms often associated with the illness.

I enjoyed meeting with Sara. We would engage in spirited discussions about Shakespeare, Elizabethan literature, and Chaucer; she would run circles around me discussing Kant, Mills, and Heidegger. She was extremely bright. We also would discuss her mental illness. Diagnosed with schizophrenia, Sara had researched the disease extensively and knew much more about the illness than I did — I could leave it at the office; she lived with it every moment of every day.

Part of her coming to understand and to accept her illness was to conceptualize her disease through a framework that she could understand — in her case philosophically and through literary metaphors.

"The weird thing is, when the voices come, I really believe them," she told me one afternoon. "It’s as if I’m a player in a Shakespearean drama. The voices are as real as your voice in this conversation." She paused. "I know that they are not real, but at the time they are as real as anything you can imagine. As real as your two hands, the sun and the moon . . ."

"I can only imagine how it would feel if everybody were to tell me that the sun doesn’t really exist, that it’s ‘all in my head.’ I can imagine myself initially trying to convince others, and then thinking that they were all ‘crazy,’ that they were somehow conspiring against me," I said.

"That’s it exactly," Sara said, "except that some folks really mess with my head by pretending to know what I’m talking about. Totally messes up my reality testing. That’s when I really start feeling paranoid. I know that they’re lying to me, but why, to ‘assess’ me? To see if I’m taking my meds and if not, to convince me to do so?" She paused. "Don’t they know that I’m assessing them?"

"I have no doubt as to your skills in assessing others Sara," I chuckled. "And as to the medications, they really do seem to be
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helping, don’t they?” I paused, and then laughed at her bemused glance. “Don’t worry; I’m not assessing your med compliance at the moment.”

She laughed in response, “Don’t worry; I would know if you were. Besides, it appears that it’s pretty obvious when I’m off my meds or they’re not working. I can’t distinguish between the real voices and the imaginary ones, so I don’t know which ones to cover up anyway,” she continued.

“I haven’t known you when you’re hearing the voices ... what do you hear? What do they say?” I asked.

She reflected a moment. “I know it sounds weird, but I see evil in people, and the voices in my head tell me that the people are bad and are going to hurt me. It’s almost as if I have to destroy them before they destroy me ... the people, I mean.” She paused. “You know me, I wouldn’t hurt a flea, but when I hear the voices, I feel more like I would be wrong not to stop the others from hurting someone else ... it’s more like I would be saving people rather than hurting them ... like if you could kill Hitler before he killed all the people in the concentration camps, would you kill him? And would that be a bad thing?” she asked rhetorically.

Such was the nature of our conversations as we struggled with Sara’s mental illness. I did not always have answers to her questions, but together we struggled to an understanding of her illness and to have her regain a more typical life in the community. Sara was a model resident and a delightful human being. She eventually graduated into fully independent living while continuing to check in on occasion at the day treatment program.

A couple of years later, I opened the local newspaper and was shocked to see Sara’s face splashed across the front page. “Woman Kills Six in Homicidal Rampage,” the headline screamed. “Dies in Fiery Highway Crash,” read the subheading. Transfixed and full of dread, I read the article. She was identified as a 27-year-old schizophrenic woman who lived alone in a neighboring town. Witnesses described a car driving at a high rate of speed down the wrong side of the four-lane expressway. The driver of the car appeared to be deliberately aiming at oncoming vehicles, several of which managed to veer away before being hit. Sara’s car had glanced off one car, which skidded and rolled, before hitting a minivan head-on. The first crash had killed an elderly man; his wife suffered a broken pelvis, bruised ribs, and multiple lacerations and was in critical condition. The second accident claimed the lives of all four occupants—a young mother, a three-year-old boy, and an elderly, unidentified woman—in a fiery explosion. Sara had died on route to the hospital, never regaining consciousness. The author of the article speculated that Sara was suicidal and had taken her life and those of others in a tragic homicidal rage.

I was stunned and heartbroken over the lost lives and grief-stricken over the death of my friend Sara. I was also angry at the portrayal of Sara as a psychotic, suicidal, homicidal madwoman. Newspapers go for sensation, often at the expense of truth and of real understanding. Though I had not seen Sara for some time, I was convinced that she had been neither suicidal nor homicidal in the time leading up to and including her tragic car crash. Rather, I suspected that she had ceased her medications and that the voices had overwhelmed her. Her words echoed in my head “... I wouldn’t hurt a flea ...” This was the Sara I had known—kind, rational, and compassionate. And it was undoubtedly the kind, compassionate Sara that drove the car down the highway in her psychotic state, truly believing that she was saving others, not killing them, that she was doing a good deed, not an evil one. The outcome was the same—unimaginable loss and grief.

The community was devastated by the tremendous tragedy and loss. Many
newspaper stories followed. Those who had known Sara just prior to the accident (some in positions where confidentiality was expected) confirmed that she had been decompensating over the previous couple of weeks and that she had likely not been taking her medications. Then there were the expected slew of articles on the fault of the mental health system, the problems associated with deinstitutionalization, and the dangers of mentally ill people walking the streets.

What was not discussed were the significant strides being made in care for folks with severe and persisting mental illness, the much more typical lives that many are leading, and the contributions that have been made and are being made by these same folks. What was not discussed was the research that suggests that folks with severe mental illness are no more likely to commit violent acts than the general population. (In the city in which this took place, there was on average one gun-related death homicide per day, and these did not receive nearly the notoriety as this tragedy.)

I still believe that psychiatrically labeled folks need to be in the least restrictive and most health-enhancing situation possible. Those with a severe and persisting mental illness need some supervision and sometimes assertive case management, but they have the same rights as the rest of us for liberty and happiness. What Sara did was tragic, painful, horrible. Should she be condemned for it? No. Should the mental health system that failed her be examined? Absolutely. What has stayed with me through the years is the ‘face’ that Sara put on schizophrenia. Now, when I read about or meet someone with schizophrenia, I look beyond the label to a whole person—a multidimensional human being with joys and passions and so many other aspects of self not defined by the condition.

The Creative Edge

It was late Saturday night when the call came in. Actually it was Sunday morning, 2 a.m. I was on call, had loads of energy, and was busy finishing up painting the living room walls. I prided myself on my ability, at times, to push through projects on little sleep. Of course there would always be the payback of exhaustion a few days later, but in the moment I could be quite productive.

“This is your answering service. I’ve got a call for you in Branderfield. Woman sounded pretty upset and wanted a crisis worker to call about her son Steve.” The operator was crisp and efficient. I retrieved the number and called immediately.

“David, you’ve got to come.” The caller was frantic. “It’s Steve. He’s out of control and made a mess of everything. I think he must have stopped taking his medication.”

Field visits in the middle of the night were usually reserved for folks who were an imminent threat to self or others, in other words, suicidal, homicidal, or psychotic to the point that they were unable to care for themselves and/or represented a danger to others. I knew the family well, having worked with Steve as a client for several years, and knew that Anne would not be calling unless it was a true emergency. My assessment was brief and to the point.

“Take a breath and tell me what’s happening,” I said.

Anne launched in immediately. “He started getting wound up about two days ago. Lots of energy, riding his motorcycle at all hours and full of ideas. Talking a mile a minute. I asked and he told me he was taking his medications. Clearly he hasn’t been.” She paused, taking a deep breath before continuing.

“Last night he didn’t come home at all, and I didn’t see him until tonight when I came down to the kitchen.” Her voice broke. “He’s been painting the living room. It’s ruined. There’s paint on everything—furniture, carpet,
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floors. He’s got no clothes on and is just covered in paint himself. He needs help,” she implored.

“Where is Steve right now?” I asked.

“He’s sitting on the couch, just staring... I covered him in my mother’s afghan, it’s ruined now anyway.” She paused. “He’s not a danger or anything, but he needs to be in the hospital.”

“I’ll be there in 20 minutes.” I paused.

“How are you, Anne?”

There was moment of silence, then a resigned sigh. “I’m fine, I just want Steve better, and I need to get this mess cleaned up... I’ll see you in a little bit,” she finished.

I had some time to reflect while making the drive to the posh subdivision. Steve, 32, had always lived with his mother. He was a very bright, passionate man who dabbled in photography, wrote poetry, and had a love of motorcycles and fast cars. He attended the clubhouse regularly and usually remained fairly stable on his medications. When he crashed, though, it was dramatic and quick.

I recalled a conversation I’d had recently with Steve. He’d been struggling with the loss of his energy as a result of the lithium he was on for the affective manifestation of his schizoaffective disorder. He was also taking Mellaril for the psychotic features of the illness.

“I know that I do better on the meds, and I feel much more stable,” he said. “But I really miss the highs. You know that’s when the poems really flow from me, and that’s when I take my best photographs. I lose my edge. You know what I mean?” It was a rhetorical question, but I responded.

“It must be really hard to lose the good high when you can be so productive. Your creativity is so clearly such an important part of who you are,” I agreed. “Unfortunately your body doesn’t know how to stop at that moderate, productive hypomanic place, and these days seems to shoot right for manic. It must be tough to lose a part of you that’s so much a part of yourself.”

“I know that I need to control the manic times with meds, but they get rid of the hypomanic times as well, and that’s where my creative edge is. I wish I could just keep the hypo and control the manic, you know?”

We’d had this conversation before. “Until the science of medications improves, Steve, it’s kind of a package. Either no meds and you get so high that you get out of control and land in the hospital; or meds and you lose both the out-of-control highs and the productive creative highs...” I paused. “It’s a tough choice.”

I wondered now, as I pulled my car into his driveway, if Steve had decided (yet again) to tinker with his meds in order to regain that creative hypomanic edge that he seemed to long for. I wondered, too, how I would feel if I needed to rely on meds to keep my moods stable but at the expense of my healthy, functional, high energy. Hypomania is great for many folks and can be a time of high productivity. But when linked with depression and/or manic episodes, it’s a red flag for bipolar illness and is pathologized; it is likewise demonized when co-occurring with symptoms of schizophrenia.

Anne quickly ushered me into the living room where I found Steve sitting, still staring into space. He appeared oblivious to his surroundings. Anne had not exaggerated the destruction of the living room. A deep blue paint was splattered everywhere. What was on the walls had been rolled haphazardly; most of the paint appeared to be on the floor, furniture, and lampshades. There were no drop cloths, and a gallon of paint was tipped over on the coffee table, still dripping slowly onto the carpeted floor below.

“He’s been like this since I called,” Anne whispered to me.

The paint was beginning to dry on Steve’s hair, which it stuck every which way. He was naked except for the paint splattered on his
body and a floral afghan loosely draped over his lap. His eyes were glassy and fixed and he had a bemused smile plastered on his face.

I was distressed to see Steve in such a state. He would not respond initially to my questions and gentle attempts at interacting with him. We sat for several minutes in silence. I took the time to compose in my head the words I would write to recommend involuntary hospitalization. The magistrate who would consider my recommendation would inevitably sign the legal documents to commit Steve to a local psychiatric facility for a 48-hour observation period. In five years of crisis work, I had never had a recommendation denied. This was less a reflection of my assessment skill than a fact of the legal system—magistrates acted largely as rubber stamps and seldom refused a mental health recommendation for an involuntary psychiatric commitment. I chuckled wryly as I recalled the colleague who had presented papers to have his dog, Casey, involuntarily hospitalized on April Fool’s day. The magistrate had filled out the paperwork and been humiliated and angered when he discovered the prank.

My reverie was interrupted by a chuckle. I glanced back to Steve, startled. His eyes were fixed on mine.

“Steve, hello,” I offered gently.
“Hello,” he responded.
“How are you?”
“How are you?” he asked in return.
“I’m here to talk with you.”
“I’m here to talk with you,” he lobbed back to me.
“I’m concerned about you.”
“I’m concerned about you,” he echoed. This was sounding familiar...

Echolalia. I’d seen it before in Steve. It was a symptom of the schizophrenia manifestation of the schizoaffective disorder. In Steve his echoing of my words often co-existed with echopraxia—a mimicking of body posture and movements. I noticed now that Steve and I were both sitting with our left leg crossed over the right. I ran my hands over my face; Steve did the same.

It was not unusual to see a decompensation of Steve’s schizoaffective illness manifesting both the affective features of his illness (in his case, mania) and the schizophrenic features (the delusions and the echolalia and echopraxia). I suspected that Steve had decreased or ceased altogether his mood-stabilizing lithium, probably in search of that elusive hypomanic high that he was grieving. As his mood elevated, Steve had likely ceased his anti-psychotic medication as well, increasing his cognitive disorganization. He’d gone this path before, unfortunately, with the same results—the need for hospitalization and stabilization. It had been a long road for Steve to be properly diagnosed. His mania had originally been diagnosed to the high sometimes attributed to the active phase symptoms of his schizophrenia. Steve’s delusions and hallucinations often had a manic quality to them. Steve experienced manic episodes concurrent with symptoms that met Criterion A for schizophrenia (in this case, delusions and hallucinations).

It was a quick assessment as far as assessments go, and the trip to the magistrate’s office was a quick one. During the late night ride on quiet back roads, I contemplated Steve’s predicament and wondered what I would do in similar circumstances. On the one hand, he seemed to understand that the mood stabilizers and anti-psychotic meds help him, and that they would help him to function within the parameters of behavior accepted in this society. On the other hand, these same medications dampened his creativity, creating in him a feeling of ‘deadness’ and lethargy. Often Steve longed for the mild highs during which time he could be so creative and productive. He was grieving the loss of control over a part of him that in earlier years had defined him. I wondered if I would so easily be able to relinquish control of the more
natural, healthy, self-induced ‘hypo’ times in my life when I have been able to complete my dissertation, renovate houses, and write into the early hours of the morning, energized and excited on very little sleep. How I would long to recall and re-experience that creative, energetic, passionate flow; and how I would grieve and resist giving it up.

At Whose Expense?
The dawn was just breaking as I left the magistrate’s office. The fall air was crisp, and I was relieved to see the oppressive heat of summer fading over the past several days. Paul had been the magistrate on duty. He was one of my favorites—he had a great sense of humor and gift for storytelling. It was a slow night and we had chatted for some time after the paperwork had been delivered to the police. They were responsible for the transport of folks legally committed to a psychiatric facility. I had reminded him of his assessment of a canine, and he returned my jab with a reminder of what he referred to as “the night of your spiritual awakening.” We had different perspectives on the case, but the facts were the same.

It had been another late night call, rousing me from a deep sleep. I’d been a crisis worker long enough now that calls didn’t pique my anxiety, and in fact I could often go on auto pilot and complete a call and even a routine field visit in a full functioning, competent manner, even while maintaining a mild, internal, sleep-like state. Over time it was a learned coping strategy and the only way to survive long on-call weekends.

This call sounded routine (if stripping someone of their right to freedom and involuntarily committing them to a psychiatric hospital is ever really routine). It was from the police, again. I’d been awakened four times already and had had to conduct a field visit earlier in the evening—I was tired. It was 3 a.m. A woman had been found wandering on a back road and she needed to be evaluated for involuntary commitment. I knew the officer well enough not to question his assessment—this would be serious.

I played Miles Davis en route to the police station parking lot, mellow enough to keep me in a mild state of sleep, yet lively enough to keep me awake to navigate the winding back roads. The officer on site was someone I had dealt with on many other occasions. Bob was a ten year veteran of the police force, and normally very mental illness-friendly. His wife was a psychiatric nurse specialist, which undoubtedly provided him with more insight into mental illness than most officers.

I was relieved to be out in the early morning when the temperature was more tolerable. The full moon cast a silver glow over the landscape, and through my open window I could hear the cacophonous buzz of the cicadas—they were out in full force.

The police department parking lot was empty except for three police cruisers; one was set off by itself, the other two had a cluster of three officers standing beside it. I pulled up to the latter, parked, and approached the officers. They appeared at ease and two were laughing at the third, who appeared to be delivering a punch line.

“G’Morning. What’s up?” I asked Bob. I recognized the other officers, Paul and Rob, but hadn’t had many interactions with either.

“The full moon and it’s keeping us busy,” he replied.

I glanced in the two cruisers.

“Where’s the woman?” I asked, eager to get home and save what I could of the night.

Bob looked uneasy. The other two officers cast sidelong glances at him. One spoke up.

“Oh, she’s in the back of Paul’s cruiser,” he replied, indicating with a nod of his head the third cruiser, parked 20 feet away.

Paul chimed in. “Yeah, go ahead and have a look ... we’ll be right over. The passenger door is unlocked.”
“Great. At least one of us wants to get some sleep tonight,” I said, yawning involuntarily and determined not to let go completely of my mild, sleep-like trance. I could feel the eyes of the officers on my back as I sauntered away and was vaguely aware that something didn’t feel quite right. Behind me, Paul made a comment to Rob, who seemed to stifle a laugh.

The streetlight cast a glare on the window of the cruiser, and I needed to peer in closely to view the occupant of the car. I was jolted out of my sleep-like trance and heard peels of unrestrained laughter from behind me.

A young woman, perhaps in her late twenties, slouched naked against the opposite door, her legs splayed open with a cross pressed tightly against her crotch. She glared at me, a wild look in her eyes.

I realized that I’d been set up. My anger at Paul and Rob was quickly replaced by concern as I recognized Kim, a relatively new member of the day treatment program. I didn’t know her well but recalled her as a bright, shy, and reserved young woman who lived at home with her mother. She was an amazing pianist, and I would always know if Kim was at the house as she would spend much of her time there engrossed in playing classical. Her father, a combat veteran of Vietnam and past police officer had committed suicide a few years back—shotgun blast to the head. Since then, Kim had divulged that she had been sexually abused by him regularly through her adolescence. Her diagnosis was psychotic disorder, not otherwise specified. She hadn’t quite fit into any of the other diagnostic categories. In my mind, the trauma that Kim experienced at the hands of her father clearly was a piece of understanding her mental condition.

Recovering from my initial shock, I glanced back at the officers. Rob and Paul were still laughing; Bob looked guilty, his eyes remaining fixed on the ground. I opened the door to the cruiser and leaned in.

I was greeted with a barrage of words delivered in a pressured, staccato-like fashion. This was a Kim I had not met.

“Don’t talk to me, get away, you will not enter into me, I know you, you’re the devil, you won’t come to me, get away, I reject you, I repeal you, you cannot have me, the Lord protects me, I am protected, you cannot have me,” she chanted, the cross clenched all the more tightly.

“Kim, I know you,” I said. “It’s David, from Yorke House, and I’m here to help you... may I talk with you?”

She continued uninterrupted, “I reject you, I repulse you, I revile you, I release you, the Lord is my protector, you cannot have me, you cannot enter into me.” I felt Kim’s eyes bore into mine. In her fixed stare I could see nothing but contempt, hate, and fear.

I made a few more futile attempts to reach Kim before concluding quickly that she needed to be more fully evaluated, medically and psychiatrically, in a hospital.

Paul and Rob had approached the cruiser at this point and were unabashedly looking in the window.

My voice was cold as I closed the door to the cruiser and quietly addressed the officers.

“Her name is Kim Smith, and as you suspect she needs to be in the hospital.” Because of confidentiality I could not share much, but I needed to convey my revulsion of their behavior. I was brief and to the point.

“Her father was a Vietnam combat vet and cop who killed himself a few years back... how would you feel if she were your daughter?”

I didn’t wait for their reply as I strode off to the office of the magistrate, whose dismissive attitude about the police behavior was “boys will be boys,” and “gotta do something to get through these long nights.”

Dawn was breaking as I made the half-hour drive home, and I reflected on the...
evening. I was appalled at the behavior of the police and their adolescent behavior and practical joking at the expense of an obviously distraught woman. They saw a young woman wandering naked on an isolated rural back road and hadn’t transported her to the hospital for any kind of an assessment for trauma or substance abuse. A crisis assessment could easily have been conducted within a medical setting. Rather, the officers had delayed more intensive assessment and evaluation in order to show her off to their fellow officers and to set me up as a crisis worker. The officers appeared to have been blinded by their objectification of the woman and her nudity, their apparent assumption of her mental illness, and the novelty of the situation. I wondered about the role of race on the experience—the three officers were white, Kim was black. Would the lack of respect and concern shown to Kim have occurred had she been white?

Appalled as I was by the inappropriate and insensitive treatment of Kim by the police, and while I would never under any circumstances condone their behavior, over time I have come to realize that theirs is incredibly difficult jobs and that folks will use humor as a means of de-escalating tension and coping with the stress of their jobs. Though healthy humor allows helpers to cope, humor should never be used at someone else’s expense or to exploit another.

Kim was hospitalized on the psych unit of a comprehensive medical center where she was also evaluated for recent sexual trauma and substance abuse. Both evaluations came back negative. With antipsychotic medication Kim recovered quickly, without much memory of her decompensation or what had triggered it. She did have vague recollections of and extreme embarrassment over her sideshow treatment by the police. Her treatment continued to focus on trauma issues and to treat her psychotic symptoms.

Lessons Learned

What do these four vignettes have in common? At the time, I would have answered that each person was diagnosed with a severe mental illness. This was the lens of pathology through which I had been trained to perceive and to work with these folks. And this is reflected in the narratives. With the wisdom of hindsight, I now see a profoundly different commonality. First, I see incredibly gifted and creative individuals. Scott was a gifted classical and jazz guitarist; Steve an accomplished photographer and painter; Sara a poet; Kim an amazing classical pianist. My training had programmed me to look at pathology and abnormal behavior and to work with the “severely mentally ill” around managing their illness and understanding its impact on their lives. I realize now that while this is vital and important, equally valuable in recovery is assisting individuals with a psychiatric label in finding creative ways to lead full, creative, meaningful lives; to see beyond the pathology and disease to the creative, energetic life force of the person in the moment.

Another lesson had to do with “us” and “them” thinking. Through the years, I have reflected on the shift in my perception when Scott first identified himself to me and later corrected my assumption that he was a staff member. The lens through which I was evaluating Scott shifted quickly, and at the time I caught myself spending less time listening to his music and more time informally assessing for symptoms of his schizophrenia. It was a valuable lesson. I recall a conversation I’d had with another staff member regarding Sara’s poetry. The staff member, a psychologist, suggested in a staff meeting that Sara’s delusional thought processes were evident in her poetry and had proceeded to deconstruct one of Sara’s poem line by line and attach the meanings to delusions and cognitive distortions. I had thought the poem was pretty good. Did knowing that the author
of the poem had a diagnosis of schizophrenia color the interpretation and simple enjoyment of the work? In this case, I believe so.

Along the same lines, I reflect now on how typical, healthy and rewarded behaviors such as hypomania in non-labeled individuals, are pathologized and medicated away in labeled folks. I do not have the stigma of psychiatric label. If I go through periods of hypomanic activity and am able to be very productive, energetic, and euphoric, the behavior and the experience is seen as positive; were I to have a diagnosis of bipolar I disorder, and therefore a past history of mania, I would be encouraged to take mood-stabilizing medication to extinguish the manic episodes and, in the process, extinguish the hypomania as well. Likewise, were the diagnosis bipolar II disorder, I would be medicated again with a mood stabilizer to extinguish the depressive episodes and the hypomanic periods as well. Hypomania is symptomatic of either of these disorders and is medicated away. In the absence of these illnesses, hypomania is not pathologized and aspects of the episodes are seen as valuable and desirable— a positive trait.

Another area that I struggle with is the contextual definition of and the unconditional pathologizing of suicide. Suicide is not always as it appears and needs to be considered within the context of the individual. I do not believe that Sara was suicidal, but died in a tragic accident caused by her delusions; it was a product of her disease of schizophrenia. In contrast to this, there are occasions, I believe, when suicide may be considered a rational, courageous, reasoned act. I recall Scott Nearing, a social reformer in the late 20th century. He was clear toward the end of his life that when life became too painful to enjoy and death was imminent, he would choose to leave life. As he neared his 100th birthday, increasingly infirm and in pain, Mr. Nearing made his intentions clear to his family that he was going to cease eating and thus allow himself to die. He followed through on his intention and died a few weeks later at home where he had spent much of his life, seemingly at peace and surrounded by loved ones. Should his death be pathologized? Should he have been evaluated for major depression? Should he have been forced into a hospital under a medical involuntary commitment so that he could live a few weeks longer strapped to machines and pumped full of medications? I would respond with a resounding “no” to each of these. Was he suicidal? In the technical sense, yes. But suicide is not always as it appears. There are times and situations when it is an act of grace, courage, and even love.

Coda - They Are Us and We Are Them

I no longer practice with consumers with severe mental illness. My “practice” now is with graduate students. I teach several sections of Advanced Psychosocial Assessment (APA) in a graduate School of Social Work. In this role, I try to convey to students the importance of conducting strengths-based comprehensive assessments that consider the whole person, including their strengths and resiliencies, and to consider and evaluate their challenges, behaviors, and symptoms within the context of their individual lives and unique experiences. We examine and engage in critical analysis of the DSM IV, cover to cover. I like to emphasize with students that many of the symptoms listed within diagnoses in the DSM IV may be thought of on a continuum and that most of us have experienced some degree of many of these symptoms. It is only when there is an increase in the level of severity of the experience of the symptom and when several symptoms cluster together and interfere with a person’s interpersonal, social,
"Us" is "Them." Working with the Psychiatrically Labeled

or occupational level of functioning that a psychiatric label is attached. I want students to identify with their own internal experience of symptoms, albeit perhaps at a lower level of severity, so that they can identify with psychiatrically labeled clients. We also explore the social construction dimension to this—culturally grounded meanings about what are acceptable and what are unacceptable behaviors.

Finally, I like to de-mystify and “normalize” psychiatric conditions by fostering an atmosphere in classes where students consider and share, as they feel comfortable, their own experiences with being assessed, assessing others, and psychiatric labels. Due to the nature of some self-disclosures, I contract with students to keep personal material discussed and shared in class confidential. While some professors bristle at this ground rule, I hold firm to it and consider it essential to ethical, effective, and meaningful teaching practice.

Students often warm up to the invitation to share by discussing medical assessments (ob/gyn, surgery, physical examinations) and academic evaluations (grades, GREs, SATs); they follow with their own psychiatric labels and experiences. The most common self-revelation among students, and perhaps the least stigmatizing, is phobias. This is followed closely by panic attacks, substance abuse and dependence, and post-traumatic stress disorder. Less commonly shared, though present in virtually every APA course I have taught over ten years, are eating disorders. I also have had some students share their struggles with bipolar disorder, with sleep disorders, and even some who have acknowledged past labels of a psychotic disorder.

I believe that the more we as helping professionals are able to internalize mental illness and put a face, even our face, on psychiatric experiences, the more effective and compassionate we will be in working with other individuals with psychiatric labels.

References


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