

Mental Health Legal Advisors Committee  
Massachusetts Continuing Legal Education

Navigating the Clinical and Legal Choices of Elders With Mental Health Issues  
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Nursing Home Hot Topics Panel  
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Today I'll be speaking to you as an advocate, not as a clinician. I do, however, have a graduate school minor in clinical psychology, as well as both paid and volunteer work experience with individuals with serious mental illnesses.

In the late 1960s while I was a college student at the University of Michigan, I had a job at the 4,000-patient Ypsilanti State Mental Hospital in the city next door. I worked on a ward of high-functioning elder women who had been in the hospital for 30-40 years sleeping 20 to a room, 10 beds lined up on each side for a total of 4 rooms and 80 women.

Primary and psychiatric care for these women was provided by a resident psychiatrist. Women lined up in the hall to see this physician and similarly to get their medications from our matron. Psychiatric assessments had not been done for them for many years. To eat, they had to go down several flights through an underground tunnel that connected our building to another where the "dining room" was sparse. The women went through a cafeteria line and got their food, no choices. Activities included a TV in a large dayroom, outside privileges to walk the campus where there was a canteen, Friday night movies and occasional outdoor events in the summer. A few worked in the back wards feeding other patients.

I was hired to help prepare these elders for deinstitutionalization by assuring they knew their ADLs and some IADLs including personal hygiene, dressing, grooming, cooking and a leisure skill.

Today I live in a nursing home where we have three neuropsychiatric rehabilitation units for individuals with brain injuries, many of whom have comorbid psychiatric and substance abuse problems. Our last unit has both long-and short-term residents, many with psychiatric illnesses. From talking to residents and family members, I learned we have individuals with a range of disorders: psychosis, anxiety, mood, personality and eating, as well as substance abuse.

The quality of care for our residents is better than at Ypsi. We have more and better trained staff to see to physical, psychiatric and rehabilitation needs. For care, there are consulting psychiatrists, neurologists, psychiatric nurse practitioners and clinical social workers who provide psychotherapy. They do regular evaluations which are developed into care plans where both pharmacological and nonpharmacological treatment interventions are prescribed.

The quality of life is also better. Residents live in doubles, providing space to make their half of the room personal. They have access to phones. The food is still institutional, but much better than at Ypsi. In my facility, we are lucky to have caring and dedicated activities professionals who see to group activities, individual needs like clothing, special food and personal interests. Family and friends visit, and when residents die, they are not buried with a number in a

graveyard behind a state hospital, as often happened before. The lives of residents are thus more normal than at Ypsi, even though spent in a nursing home.

Do I believe the elders with psychiatric illnesses in my facility could live in the community with supports and services? With only a couple of exceptions they would be poor candidates for living outside. Physically, some are not ambulatory and are Hoyer transfers. Most have complex medical conditions - comorbidities, like cancer or COPD with 24 hr oxygen, and need medical care. Several have been so psychotic, delusional, hearing troubling voices or even hardly aware of their own existence. One prior resident was very paranoid with a history of multiple suicide attempts that had left her a partial amputee. One was ambulatory, but extremely confused wandering incoherently or, in another case, scrubbing the floor of his room for hours. One had been living and working successfully in the community, but her meds failed. She was suffering terribly and needed constant oversight, hospitalization and repeated attempts to find a medication that would stabilize her.

An elder woman with bipolar disorder in another facility tells me she prefers to live in a nursing home, as she feels safer and protected from her aggressive impulses when her mood swings. Some residents with addictions benefit by having medication given under supervision. All of the above elders have chronically severe psychiatric illnesses and are among the sickest residents. They could not survive with community-based services as they need 24 hr access to care.

Other elders that I believe could live in the community are the following: a woman who was alert, ambulatory and told me she had schizoaffective disorder, hearing voices which traumatized her, especially after going to Mass. From the day I first saw her on my unit, she was desperately trying to be discharged to her own apartment, have her own money and control over her life. I always felt she could live outside and, after a couple of years of care, she was finally discharged, telling me she was going to a rest home.

Another woman seemed to have primarily a personality disorder. She was ambulatory, anxious and wanted to stay in bed at all times. She had a husband she wanted to live with, but she died, never getting out of an institution. I've always wanted to know more about her and wondered if, with PCA cueing and supervision at home, she might have been reunited with family. A clinical social worker I know who practices exclusively in nursing homes told me she has met other elders she believes could live in the community.

Housing and supports, after medical need, are the biggest barriers to living outside a nursing home. Affordable long-term options include subsidized housing, such as public elderly/disabled, section 8 certificates for market rate rents and PACE for assisted living. There are also HUD supported housing for the elderly, adult foster/family care, group adult foster care, rest homes, and group homes for the mentally ill, the last of which, however, are intended to be transitional.

Many individuals would do well with HCBS, including nursing visits for medications, rapid response approaches to crises, support groups and day programs. Mobile vans could provide some of this elder psychiatric care, making more housing options viable, consonant with the principle of Olmstead and Community First of living in the least-restrictive environment.

What does the future hold? A controversial January 2015 article in JAMA by some Penn bioethicists that calls for the development of new inpatient hospitals for those with psychiatric disabilities shows how far we have to go. Individuals should first be getting enhanced services in the community, as with segregation people would be lost, ignored and forgotten. The likelihood is rather that nursing homes will continue to provide care for some elders with mental health issues, and thus, we need to continue to identify ways that care and life there can be improved.

Problems I see that still need to be addressed include the fact that nursing home residents end up with psychiatric diagnoses they never had before. Many residents suffer from culture shock and a lack of empowerment while trying to assimilate to institutional life. Some may be labeled anxious or depressed. Some resist, are noncompliant and refuse treatment to reassert their agency which is normal. Staff react by designating these coping strategies they don't like as behaviors. One psychologist said the real diagnosis is nursing-home-induced-PTSD.

The number of residents I have met with a diagnosis of bipolar is astounding, given what a recent article in McKnight's LTC news (2/13/15) describes as a disorder that still has "definitional ambiguity." A woman religious who had had a successful career as a social worker, all the while hearing voices was, after a stroke, diagnosed as schizophrenic. A basic tenet of the international Hearing Voices Movement is that anyone who copes with voices successfully does not have a medical condition, but only a difference.

This pathologizing leads to an ever-expanding population of residents with psychiatric illnesses, stigma and unnecessary drugging. International staff in my facility have reported to me that they find this phenomenon unique to the U.S. and one that victimizes people.

Another area of concern is that the current level of meaningful engagement is insufficient. A lack of enough staff leads to isolation, boredom, depression and attention-seeking. When staff fail to respond, some residents have frequent outbursts and/or request contraindicated items: food, unnecessary pain and anxiety drugs, and even hospitalization to comfort themselves. This is a systemic problem in nursing homes across the country.

Roommate assignment can be poor, as in another facility where an alert resident with a psychiatric disability was living with a dying roommate, the stress of which led to decompensation until a better match was found. Other problems I've heard of include Rogers guardianships not being kept timely and consulting psychiatrists who rarely see residents, but rather just get updates about them from staff. A resident in another facility complained to me that she had to get information about side effects of her drugs from LPNs on her unit in whom she had no confidence.

There are several other areas where care can be improved. Residents who get psychotherapy should have confidentiality, rather than having notes from sessions put into their medical charts available for all staff to read. Genuine problems occur with facility living, and residents have the right to discuss them without fear of retaliation. Traditional ideas of behavior management, a token economy, and levels of privileges should be updated to include the wellness, peer support, empowerment and recovery models used in the disability community. When there are international staff who come from countries where mental illness is extremely stigmatized or

where their culture is more authoritarian, cultural competency about acceptance and progressive ideas on causes, treatment and recovery need to be assured.

A related concern I have for individuals with mental illnesses is the often reluctance of physicians and management of some nursing homes to discharge them. One woman, during her stay in a facility for short-term orthopedic rehab, could not convince staff to provide the care she needed for her ADHD: seeing her outside provider, taking her medication and needing information written down because of her inability to pay attention to and remember details. She wanted to return to her apartment to be with her partner, but was told her she was too confused and protective services would be called if she tried to leave. Clearly, management didn't understand her disorder, had failed to provide proper care, and had low expectations of her ability to live in the community. I personally intervened by calling and talking to the DON about how the facility had been violating the woman's rights under the CMS CoP and she was discharged the next day.

Another woman with bipolar disorder was forced to agree to be in adult group foster care in order to be allowed to be discharged from a nursing home. When she later joined the Medicare-Medicaid dual-eligibles OneCare program she was liberated from this restriction and is now an active disability advocate in MA. Both women are currently thriving.

These areas where care and life could be improved do not take away from the fact that elders with mental health issues are receiving substantively better care and leading better lives in nursing homes than before in state mental hospitals. We need to continue moving forward with community care that has been proven to work, but is underfunded and in short supply. Community care will maximize personal autonomy and allow people to participate fully in their communities.

Thank you for taking an interest in this too-often-stigmatized and disregarded group of people.