

Institutional Neglect of Anosognosia Is a Critical Barrier in the Treatment of Psychosis Related Disorders

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The neurological symptom of anosognosia, which occurs in 50% to 80% of individuals who develop schizophrenia and other psychosis spectrum disorders, is the primary barrier to receiving life-saving medical care. Anosognosia robs a person's ability to recognize that they are sick¹ and can block caregivers and families from obtaining treatment for their loved ones.

Despite alarming rates of anosognosia among individuals with serious mental illness (SMI), there is little acknowledgement in the medical community that this cruel symptom exists. The result of this underrepresentation in medical research is that there are no treatments. Decades of neglect and inattention have contributed to systemic institutional discrimination and mental health systems that are designed to fail patients suffering anosognosia.

Clinical trials require patient consent and awareness of illness. Antipsychotic medication has only been studied in a small subset of psychosis spectrum patients who realize they are sick and can communicate their symptoms—essentially individuals with hallucinations who realize they are hallucinating. It comes as no surprise that decades of drug development have produced dozens of antipsychotics that treat hallucinations but do little for patient insight or for negative symptoms in general. Complexities in schizophrenia are so challenging for researchers that most clinical trials fail, with only 20% to 30% of patients showing significant improvement over a placebo.²

Psychiatrists, hospitals, and clinical staff are not well trained or equipped to manage patients with poor insight, and few institutions have effective protocols for engagement, medication, or therapies for anosognosia patients. The sickest psychiatric patients, those unable to recognize their illness, have been effectively carved out of the healthcare system.

Obtaining life-saving medical care for patients with anosognosia has become increasingly difficult. The deinstitutionalization of treatment for SMI patients that began during the 1980s intended to move patients to less restrictive settings. Unfortunately, this well-intentioned effort resulted in simply ending treatment for most of the SMI population. This elimination of therapeutic psychiatric programs also coincided with civil rights groups limiting access to involuntary treatment.^{3,4} The combined result has been severe neglect of those with untreated psychosis and ultimately discrimination against anosognosia. Individuals with treatable conditions have been sentenced to homelessness, incarceration, isolation in their family's basements, or lying on a slab in the morgue.⁵⁻⁸

The burden of trying to care for society's sickest patients, those who refuse treatment as a symptom of their illness, has largely fallen on mothers.⁹

In states and counties with favorable treatment laws, the presence of psychosis, deteriorating mental health, or even the risk of deteriorating without treatment grants individuals the right to receive involuntary services. In such states and counties an avenue exists to obtain appropriate care for SMI patients with anosognosia.¹⁰

Unfortunately, most areas have woefully inadequate thresholds to receive treatment. Many regions in the US require outwardly dangerous, suicidal, or violent behavior. In some states, the assessment of the individual is made by law enforcement rather than a medical professional. Even regions with reasonable treatment laws lack crisis teams and hospital resources to support them. Thus, the opportunity for individuals with anosognosia to receive effective treatment often depends on their location.¹¹

Most families and caregivers trying to help loved ones with anosognosia face dismissiveness, inattention, and even hostility from community services. Crisis teams, including those enlisted by the new 988 service, refuse to send help unless the suffering individual in crisis is capable of voluntarily requesting the help themselves. This puts family members, especially mothers, in perilous circumstances.

Families whose loved ones do qualify for involuntary evaluation are often excluded from the evaluation process; a problem that is frequently blamed on widely misinterpreted "HIPAA guidelines."

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Families recount psychiatric hospitals refusing to even acknowledge if their loved one is an admitted patient. They are left in the dark, unable to help their incapacitated family member.

This incorrect misapplication of “HIPAA” regulations is just one element of a much broader range of discriminatory practices against those with the symptom of anosognosia. The patient experience and interaction with families are very different for those suffering head trauma, a stroke, or any other illness requiring medical hospitalization of an incapacitated person who has lost their decision-making capacity. This disturbing trend continues after hospital discharge and into outpatient settings where caregiver inputs are further stifled and ignored, often to the detriment of the patient.

Community mental health programs, in general, are tailored to patients with insight. Even regions that have implemented Assisted Outpatient Treatment, programs intended to enforce court-mandated outpatient participation, offer mostly voluntary treatment options. Many services are only available if the patient understands and agrees they need them. Services like medication management, direct medication observation, assertive community treatment team services, counseling for psychosis, and family therapy are vital to anosognosia treatment. Because these are often voluntary programs, these services are usually unavailable to patients who would benefit the most.

Many programs require “patient-centered goals” activities where an assigned case manager must complete an annual report for each patient in the community clinic's electronic health database. The process is reminiscent of corporate employee performance management systems. When asked to describe their health goals, the individual with anosognosia inevitably responds that they want “to come off medication, get out of court-ordered treatment, and get my own apartment.” Meanwhile, the quiet caregiver observing this interchange is terrified that the case manager might condone or encourage these ideas. These “patient-centered” processes are clearly designed by corporate administrators trained in general mental health with almost no awareness of managing patients who have severe brain illness and a lack of awareness they are sick.

Elderly patients experiencing dementia do not face the same obstacles to treatment, despite the commonality in symptoms and presentation. Caregivers of patients with psychosis and anosognosia regularly encounter dismissiveness, hostility, arrogance, and an attitude of “I'm a doctor, you're not.” Those able to find meaningful recovery for their loved ones tend to be mothers who have refused to accept what one mother describes as an “onslaught of caregiver gaslighting.” Few psychiatric providers are able and willing to partner with families and caregivers struggling with anosognosia in a family member.

Many private outpatient providers turn away SMI patients and will not accept court-mandated patients. They treat patients who are cooperative, interested in achieving wellness, that show up to appointments and are appreciative of treatment. Treating SMI patients with anosognosia is a different experience. There is no insurance reimbursement for frequent caregiver phone calls and the additional time required to engage difficult patients and manage the multitude of medications that most psychosis patients require to achieve meaningful recovery. There is no added reimbursement for coordinating treatment plans and prescriptions for patients making frequent trips to the hospital or for completing evaluation papers for mental health courts. Savvy and resourceful families that finally locate a skilled outpatient psychiatrist are dismayed to learn that many only accept private payment. Standard insurance reimbursement rates, even through private plans, are not enough to support the operating costs of a private practice treating SMI patients.

Hardly any outpatient psychiatric providers are certified to prescribe clozapine, the only Food and Drug Administration–approved antipsychotic for treatment-resistant schizophrenia and a potential treatment for anosognosia. In the United States, clozapine is woefully underused compared with other advanced countries.¹² Prescribers' concerns around the complexities of monitoring clozapine perpetuate what has been described in the literature as “clozapinophobia.”¹³ This itself represents an obvious exclusion of the sickest patients from most psychiatric practices.

Another key challenge with anosognosia is the inability for patients to recognize improvements that come with effective treatment. For example, patients who have a reduction in auditory hallucinations will determine that “people just stopped harassing me” or draw similar conclusions rather than associate the reduction in symptoms to antipsychotic treatment. Patients returning to work or school usually attribute the regained function to simply “trying harder” rather than the result of effective medications.

What patients with anosognosia do recognize, however, is medication adverse effects. This is another area where mainstream psychiatry has failed its sickest patients and another source of medical discrimination. Antipsychotic-induced weight gain, for example, often goes untreated. Anosognosia patients routinely say, “these medications don't do anything, they just make me tired and fat.” Use of the common medication metformin is a well-established standard of care to prevent diabetes and metabolic disorder in patients taking certain antipsychotic medications.^{14,15} However, when asked to prescribe metformin, most psychiatrists offer a simple response of “I don't prescribe that,” forcing their patients to engage a second provider from internal medicine who must, in turn, be comfortable treating severely ill psychiatric patients.

Clozapine especially, the most promising medication for anosognosia,^{16,17} has a unique side effect profile that requires effective management and prevention of adverse effects like drooling and severe constipation.¹⁸ More effort is needed to study and develop medications that facilitate or optimize the use of clozapine, specifically. Other innovations in clozapine patient care such as point-of-care finger-prick monitoring to detect neutropenia¹⁹ or to measure clozapine serum levels,²⁰ along with intramuscular injectable clozapine formulations,²¹ need to be prioritized for Food and Drug Administration approval and clinical implementation.

Movement disorders, seizures, sexual dysfunction, and sedation are other adverse effects that must be effectively addressed if patients with anosognosia will adhere to treatment. Because few psychiatric prescribers are willing, able, or confident in comprehensively managing the whole patient, the result is usually more suffering, more refusal of medications, and worse patient outcomes.

Appropriate treatment can greatly curtail the suffering of our most vulnerable SMI populations and their families. Given that individuals with untreated SMI typically experience years, if not decades, of repeated hospitalizations, incarceration, and homelessness, the potential positive impact of treating anosognosia on the medical system of care, and on society as a whole, is immeasurable. It is imperative that the medical community consider implementation of the following measures:

- Anosognosia deserves its own diagnosis. The diagnosis needs an elevated classification that is commensurate with the inherent risks—risks not just for the patient, but for surrounding family members and even the greater society. Patients experiencing the neurological symptom of anosognosia face grave risks of nonadherence, which leads to prolonged psychosis and further brain damage.
- The diagnosis of anosognosia deserves a higher rate of reimbursement for treatment services. Patients diagnosed with anosognosia

should be granted longer hospital stays and higher levels of care upon discharge. Payors should authorize longer and more frequent outpatient visits and anosognosia should qualify individuals for long-term care programs beyond traditional SMI services. Physicians prescribing clozapine should receive a higher level of reimbursement that is commensurate with clozapine's added requirements to monitor and treat adverse effects. Doctors should be incentivized to accept patients with court-mandated treatment orders. Physicians willing to treat our sickest patients deserve higher compensation because it is very difficult.

- Anosognosia deserves clinical study. It is vital to the care and treatment of brain illness in our society that we learn how to treat this condition and engage patients and their families in effective treatment. Training of psychiatrists and clinical staff needs to specifically emphasize partnering with caregivers, parents, families, and guardians. Patient accounts of illness are not accurate and can be convincingly guided by delusions. Specifically, the delusion that they are not ill in the first place and do not need medications.
- Clinical models for patient care need specific training on anosognosia that provides a working knowledge of the condition and lifesaving techniques, such as Dr Xavier Amador's LEAP method (Listen, Empathize, Agree, Partner) to improve patient engagement and outcomes.²² A diagnosis of anosognosia with SMI should facilitate the appointment of a guardian ad litem, in the same manner that occurs more seamlessly with dementia patients. Psychiatric patients with anosognosia should automatically qualify for medication management and observation services. Family and caregivers should be provided with training, counseling, home visits, and respite care, comparable with memory care supports offered to family members caring for elderly parents.

Many psychiatric clinicians have never been trained on anosognosia, and most have never heard the term. However, this neurological symptom is single-handedly responsible for the majority of deaths, violence, mass incarcerations, homelessness, and disability associated with SMI. Caregivers of loved ones in psychosis witness the field of psychiatry abandoning the most difficult patients. More resources, attention, funding, and research are needed for programs that treat people with SMI and anosognosia. We must put an end to having the sickest among us languish untreated, unstudied, and dismissed to the streets or to overwhelmed mothers.

This blatant institutional discrimination has deep roots. Change will only come about by acknowledging that anosognosia exists, it is dangerous, widespread, and that above all, it deserves medical attention.

Rachel Streiff, BS, serves as an administrative leader for Team Daniel Running for Recovery from Mental Illness, an advocacy group promoting safe use of clozapine, the most effective treatment for both psychosis and anosognosia. Through her training as a biomedical engineer and Six Sigma Black Belt, she has partnered with Dr Robert Laitman and Dr Ann Mandel to monitor patient outcomes, analyze clinical data, and publish results from their clozapine-centered medical practice. She also serves as a volunteer to help patients, families, and caregivers through local organizations and nationally through The CURESZ Foundation and Families for Treatment. Her statements represent a growing voice among caregivers for loved ones with schizophrenia and related psychosis spectrum illnesses who have been harmed by decades of worsening neglect and discrimination.

Ms Streiff became a mental health advocate after a family member developed psychosis with anosognosia. After a difficult

2-year period, she was able to secure effective treatment. Her family member has since made a full recovery from both conditions because of both Assisted Outpatient Treatment and a clozapine-centered approach. She can be reached at rachel.streiff@protonmail.com.

AUTHOR DISCLOSURE INFORMATION

The author declares no conflicts of interest.

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