Unawareness as a Barrier to Treatment in Patients with Schizophrenia

A Conceptual Analysis

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ABSTRACT
This article explores the phenomenon of unawareness in individuals with schizophrenia. Definitions, individual examples, prevalence data, suggested causation models, societal costs, and recommended treatment interventions are reviewed. In addition, strategies specific to advanced practice nurses who work with patients with severe and persistent mental illness are discussed.

I suppose it is tempting, if the only tool you have is a hammer, to treat everything as if it were a nail. (Maslow, 1969, pp. 15-16)

Noncompliant, difficult, lacking insight, and poor judgment are terms commonly used in describing patients resistant to psychiatric services. These individuals exhibit severe mental impairment, endlessly cycling between group homes, shelters, psychiatric hospitals, emergency departments, and jails. They miss scheduled appointments, decline pharmacological and psychosocial interventions, and adamantly disavow the necessity of treatment. The onus falls to the individual who declines clinical opinion, leaving clinicians to shrug and scribble “lacks insight,” a judgment McGorry and McConville (1999) believed providers ascribe when patients disagree with a professional’s opinion. The treatment team is left at the crossroad, concluding the patient’s poor decision making is due to a lack of insight and global unawareness.

Rather than being an individual’s deliberate choice, perhaps unawareness is another indicator within the constellation of symptoms that form thought disorders. The World Health Organization (WHO) (n.d.) defines schizophrenia as a severe mental disorder that affects thinking, language, perception, and sense of self, and often includes hearing voices or delusions. Most clinicians acknowledge the deception of auditory hallucinations, the paranoia of government tracking, the suspiciousness of mind reading, or delusions of grandeur as symptoms of cognitive turmoil; however, the simple act of denying illness or deferring treatment frequently goes unrecognized as a demonstration of the disease. Is it not possible that disease unawareness is a manifestation of distorted perception rather than purposeful behavior?

This article explores the phenomenon of unawareness in individuals with schizophrenia. Definitions, individual examples, prevalence data, suggested causation models, societal costs, and recommended treatment interventions are reviewed. In addition, strategies specific to advanced practice nurses (APNs) who work with patients with severe and persistent mental illness are discussed.

DEFINITIONS
The worst pain a man can suffer: to have insight into much and power over nothing. (Herodotus, n.d., para. 1)

It has been suggested that unawareness in those with a serious and persistent mental illness may actually be anosognosia. According to Xavier Amador:

People with this syndrome do not believe they are ill despite evidence to the contrary. People will come up with illogical and even bizarre explanations for symptoms and life circumstances stemming from their illness along with a compulsion to prove to others that they are not ill, despite negative consequences associated with doing so. (“Anosognosia,” 2001, para. 3-4)

These perceptual disturbances are not uncommon. Stroke patients and patients with Alzheimer’s disease, traumatic brain in-
jury, and brain lesions are just a few of the patient groups that exhibit agnosia as a consequence of their brain disorder. Agnosia, a word often used interchangeably with anosognosia, is the inability to recognize objects or persons despite knowledge of said object or person. Anosognosia, a specific form of agnosia, is defined as non-knowledge or a loss of knowledge (“Anosognosia,” 2001). Thus, for individuals with a thought disorder, anosognosia means lack of knowledge or awareness of an internal behavior or thought—these individuals lack a feedback system about their own condition.

**EXAMPLES**

Examples of global unawareness and perceptual disturbances exist in ancient times as well as today. For instance, in Mark 8:22 of the King James Bible, Jesus applied spit to a blind man’s eyes. The man immediately announced that he had been healed of his blindness, but he observed men walking as trees. Jesus again laid hands on the man, resulting in the man reporting full restoration of his sight. For some, the first touch is healing of sight and the second touch is healing of perception, or visual agnosia (Kliska, 2009).

In another historical example, the ancient Roman philosopher Seneca (n.d./1917) described Harpaste, a woman living in his home who denied her blindness and instead complained of persistent darkness. To everyone’s folly and consternation, Harpaste demanded the staff increase the light and rearrange her surroundings.

A modern example is that of the Unabomber, Theodore Kaczynski. Kaczynski vigorously fought all attempts by his defense team to present an insanity defense, despite the possibility that if found sane, he would certainly face the death penalty. Kaczynski, who feared being labeled a “sickie,” refused any evaluations for which the outcome might be a mental illness diagnosis (Amador & Paul-Odouard, 2000).

Ultimately, Kaczynski sought to have his defense team fired (Amador & Paul-Odouard, 2000), but his request was overruled. The consensus of the prosecuting and defense teams was that although competent for trial, Kaczynski suffered from paranoid schizophrenia. A life sentence was offered and accepted. Since then, Kaczynski has filed various appeals on the grounds that he was forced to accept a plea based on a nonexistent mental impairment (Amador & Paul-Odouard, 2000).

**PREVALENCE**

Although the term anosognosia is used infrequently in the clinical setting, this is not the case in the research setting. Studies documenting the phenomenon of unawareness are abundant, with examples spanning more than four decades. In 1973, the WHO’s International Pilot Study of Schizophrenia found 81% of participants denied having a mental illness despite being diagnosed with one. Similarly, 89% of individuals with schizophrenia examined by Wilson, Ban, and Guy (1986) refuted results that supported a diagnosis of schizophrenia and the symptoms that accompany the disorder. Research conducted by Amador et al. (1994) ascertained that 60% of those with moderate to severe mental illness were unaware of their disorder or its symptoms. In fact, lack of awareness is considered one of the 12 hallmarks that differentiate schizophrenia from other disorders with similarly occurring symptoms (Carpenter, Strauss, & Bartko, 1973).

Keefe, Poe, McEvoy, and Vaughan (2003) described patients with paranoid schizophrenia who exhibited autonoetic agnosia, which is the inability to identify self-generated actions. This includes an inability to perceive the positive symptoms associated with thought disorders (e.g., paranoia, grandiosity, hallucinations) or the negative symptoms of schizophrenia (e.g., alogia, affective blunting, anhedonia). Sevy, Nathanson, Visweswaraiah, and Amador (2004) reported that “32.7% of patients with schizophrenia lacked awareness of having a disease, 58.2% failed to recognize certain symptoms, 18.4% failed to acknowledge treatment response, and 41.8% lacked awareness of social consequences” (p. 17).

Despite schizophrenia being a disease inherent of distorted perceptions and altered insights, there remains exasperation among professionals when individuals reject the existence of the disease and its accompanying symptoms. Amador (2006) proposed the rationality of avoiding treatments if one claims to be healthy.

**CAUSATION MODELS**

A review of the literature reveals four predominant models that attempt to explain causation of anosognosia in schizophrenia. Not mutually exclusive, the models or theories are (Rickelman, 2004):

- Psychological defense model.
- Cognitive deficit model.
- Theory of chemical dysregulation.
- Neuropsychological deficit model.
Psychological Defense Model

The psychological defense model was the prevailing explanation until the 1990s. This model assumes that an individual’s failure to recognize his or her illness is a conscious (or subconscious) choice, or a Freudian demonstration of ego avoidance to preserve one’s self (Rickelman, 2004). Research since the 1990s suggests ego avoidance may play a role; however, there is greater support that neurochemical, neuroanatomical, and neurocognitive factors provide a better explanation for anosognosia (Amdador & Paul-Odouard, 2000).

Cognitive Deficit Model

The cognitive deficit model is based on findings that those with anosognosia demonstrate decreased executive functioning on standardized tests. For example, those with pervasive anosognosia scored lower on standardized cognitive functioning tests than those who were asymptomatic (Lysaker, Bell, Milstein, Bryson, & Beam-Goulet, 1994). Individuals with schizophrenia and poor insight also performed lower than expected on tests measuring verbal and spatial ability as well as working memory, suggesting that individuals displaying an inability to process executive information are also unaware of perceptual dissonance (Donohoe, Corvin, & Robertson, 2005; Lysaker et al., 1994).

Theory of Chemical Dysregulation

Contemporary research shows the relationship between schizophrenia and dopamine, serotonin, and glutamate dysregulation. Does this mean that thought disorders are simply chemical imbalances needing chemical correction? If this were the case, then the advent of serotonin-dopamine antagonist, partial agonist, or psychoactive agents that protect glutamate would correct the dysregulation and thus resolve the symptoms, essentially curing the disease. We know this is not the case. Serotonin-dopamine antagonist and glutamate protecting agents have provided benefit yet have not been proven curative (Lieberman et al., 2005). Thus, schizophrenia is more than a disorder of chemical dysregulation.

Neuropsychological Deficit Model

The fourth and most recent causation model is the neuropsychological deficit model, which suggests anosognosia occurs in relationship to damage to the brain. Flashman, McAllister, Andreason, and Saykin (2000), Flashman and Green (2004), and Steen, Mull, McClure, Hamer, and Lieberman (2006) established that individuals with anosognosia and schizophrenia had smaller brain size or intracranial volume; structural or volumetric differences in the frontal, temporal, and parietal lobes; smaller hippocampal volume; larger ventricles; reduced synaptic tissue; and an overall reduction and disorganization of synapses.

The results from a study performed by Flashman et al. (2001) have been given significant credence due to the preciseness of the study’s methods. The researchers evaluated patients with schizophrenia and attempted to find a relationship within eight subregions of the frontal lobe and the incidence of unawareness. The researchers observed an inverse correlation in awareness and the volume of the mid-frontal, right rectus, left anterior, and superior frontal gyrus volume.

In addition, due to the painstaking specificity of their subregional tracking, the researchers were able to discover subtle nuances in types of anosognosia (Flashman et al., 2001). For instance, individuals with near global unawareness of their disease were likely to have volumetric disturbances in the mid-frontal, right rectus, and left anterior cingulate gyrus, whereas less global anosognosia was attributed more often to volumetric changes in the superior frontal gyrus (Flashman et al., 2001).

Despite the availability of superior diagnostic tools that have led to burgeoning evidence weaving a relationship between anosognosia in schizophrenia and irregularities in the brain, a true causal explanation about unawareness or anosognosia does not yet exist.

Societal Impact

People believe I am what they see Me as, rather than what they do not see. (Walsch, 1996, p. 28)

Regardless of which model is correct, research supports the presence of anosognosia in schizophrenia, and empirical data reflects poor outcomes in those with untreated schizophrenia. Poor outcomes are not without costs. Expressly, schizophrenia has a known economic burden to society. The care for those with schizophrenia, as reported in 2002, was estimated to cost $62.7 billion (Wu et al., 2005). This estimate included the costs of medications as well as the cost of direct, outpatient, inpatient, and long-term care.

In his book, Surviving Schizophrenia: A Manual for Families, Patients, and Providers, Torrey (2006) noted that 6.1% of those with schizophrenia are in jails or prisons, 4.5% are homeless or living in shelters, 12% live in hospitals or nursing homes and 18% live in group homes. These costs also add to the economic burden of care. Recognizing the preva-


KEY POINTS

1. Unawareness, or anosognosia, is often an additional symptom associated with the constellation of symptoms that form the syndrome of schizophrenia.

2. Four models that attempt to explain anosognosia in schizophrenia are the psychological defense model, cognitive deficit model, theory of chemical dysregulation, and neuropsychological deficit model.

3. Rather than viewing nonadherence as an intentional behavior, clinicians should recognize anosognosia as a complex and multidimensional neurological, anatomical, chemical, cognitive, and psychological phenomenon.

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lence of this disease indicates the need for ongoing engagement and treatment of individuals with schizophrenia.

Beyond economic burden or patient prevalence is the risk of harm to self and others that accompanies schizophrenia. A cause for disconcertion is the fact that suicide is one of the leading causes of premature death in individuals with schizophrenia. The reported success rate for suicide among individuals with schizophrenia is 10% to 13% versus 0.1% among the unaffected population (Brown, Inskip, & Barraclough, 2000).

Violence is also associated with schizophrenia. Woods, Reed, and Collins (2003), Buckley et al. (2004), and Bjorkly (2006) reported that although the overall risk for violence in those with schizophrenia is low, individuals with schizophrenia who had engaged in violent behavior lacked both insight about their behavior and awareness of their disease. With an increased risk of harm to self and others in those with anosognosia, clinicians must avoid exasperation and instead factor unawareness into patients’ treatment plans.

RECOMMENDATIONS FOR CLINICIANS

The first recommendation is for providers to develop awareness. Clinicians are challenged to recognize anosognosia as a complex and multidimensional neurological, anatomical, chemical, cognitive, and psychological phenomenon (Amador & Paul-Odouard, 2000). A second recommendation for clinicians is to demonstrate empathy for patients with schizophrenia and anosognosia. In making this point, Amador (2000) refers to a quote made by the character Atticus Finch in To Kill a Mockingbird: “You never really understand a person until you consider things from his point of view—until you climb into his skin and walk around in it” (Lee, 1960, p. 30).

Clinicians should use standardized tools that quantifiably assess and identify those with limited insight. Some of these tools include the Scale for the Assessment of Unawareness of Mental Disorder (Amador et al., 1993), the Awareness of Insight Tool (David, 1990), and the Insight and Treatment Attitude Questionnaire (McEvoy et al., 1989).

Consumer education, a core skill at which APNs excel, often is not enough when confronted with patient unawareness. According to Amador (2000), “education about the illness does not translate into insight into one’s own illness” (p. 54). Amador (2009) is not only a noted expert in the study of anosognosia and schizophrenia but also the sibling of someone diagnosed with schizophrenia. The LEAP Institute was developed after Amador (2000) noted that reflective listening proved successful in this patient population. The LEAP technique emphasizes Listening, Empathizing, Agreeing, and Partnering with those with anosognosia.

A similar technique believed beneficial in this population is motivational interviewing, described by Miller and Rollnick (2002). This technique uses patient-centered counseling to elicit change and resolve ambivalence by avoiding coercion, confrontation, judgments, or persuasion. Furthermore, the relationship between providers and patients is often seen as a partnership (Miller & Rollnick, 2002). Using reflective listening techniques, clinicians seek to understand patients, express acceptance, and affirm patients’ ability to choose and engage in self-direction. Emmons and Rollnick (2001) established that providers who applied these techniques encountered less patient resistance to change.

Rickelman (2004) advises that less emphasis should be placed on what clinicians may perceive as problematic and greater focus should be placed on what patients identify as distressing. For instance, if patients are expressing concern about insomnia, hallucinations, or paranoia, clinicians might ask what interventions have historically worked or not worked to ameliorate these symptoms and thus have patients direct their care.

Another successful strategy is the use of self-help groups such as Schizophrenics Anonymous.
SUMMARY

The goal is to transform data into information and information into insight. (Fiorina, 2004, para. 11)

The terms agnosia and anosognosia are recognizable concepts used in field research but less frequently used in clinical settings. Rather than viewing nonadherence as an intentional behavior, clinicians should recognize unawareness in schizophrenia as a neurological expression of the disease. When possible, clinicians should avoid terms such as noncompliance, poor insight, or lacking judgment and instead work toward familiarization with the neurological disturbance that is anosognosia. Furthermore, clinicians should integrate anosognosia into daily terminology and include diagnostic tools that assess for anosognosia when evaluating patients.

With greater understanding of anosognosia, APNs diminish opportunities for subjectivity, instead implementing evidence-based strategies that identify unawareness. Consequently, the expectation is improved patient assessment, planning, and treatment, thereby reducing anosognosia’s role as a barrier to treatment.

REFERENCES


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