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Improving lives affected by schizophrenia-related Brain disorders

August 28, 2018

Director Robert R. Redfield, MD
U.S. Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, GA 30329

RE: Inclusion of Schizophrenia in National Neurological Conditions Surveillance System (NNCSS)

Dear Director Dr. Redfield,

On behalf of the Schizophrenia and Related Disorders Alliance of America (SARDAA), we are writing to respectfully request the inclusion of schizophrenia as an eligible condition in the National Neurological Conditions Surveillance System (NNCSS) as authorized under the 21st Century Cures Act (PL 114-255).

Founded a decade ago, the Schizophrenia and Related Disorders Alliance of America promotes improvement in lives affected by schizophrenia-related brain illnesses (mental illnesses involving psychosis). SARDAA promotes hope and recovery through support programs, education, collaboration, and advocacy. Our vision is that every person living with schizophrenia-related brain illness receives respect, appropriate treatment and an opportunity to live a meaningful and satisfying life in a compassionate community free of discrimination.

What is the Personal and Public Health Impact of Schizophrenia? There are published studies suggesting that patients with schizophrenia die on average 28.5 years sooner than other Americans.¹ Sadly, 40% of this is due to suicide,² with 5% lifetime completed suicide rates in

¹ Olfson M, Gerhard T, Huang C, Crystal S, Stroup TS. Premature Mortality Among Adults With Schizophrenia in the United States. *JAMA Psychiatry*. 2015 Dec;72(12):1172-81. PMID: 26509694

² Bushe CJ, Taylor M, Haukka J. Review: Mortality in schizophrenia: a measurable clinical endpoint. *J Psychopharmacol*. 2010;24(4_suppl):17-25. doi:10.1177/1359786810382468

schizophrenia,³ most being shortly following illness onset, with suicide attempts at 25-50%.^{4, 5} Whether patients receive timely, appropriate treatment has great consequences. After the first episode of schizophrenia, not taking any regular antipsychotic medication is associated with a 12-fold increase in the relative risk of all-cause death and a 37-fold increase in death by suicide.⁶ Unfortunately, up to 40% of individuals with schizophrenia are untreated (Treatment Advocacy Center).⁷ Eleven percent of the homeless population have a diagnosis of schizophrenia, with higher rates in younger persons (13% for 18–30 years old; 21% for 31–40 years old), women (twice the rate of men) and the chronically homeless (18%), with slightly less than half not receiving treatment.⁸

Unfortunately lack of treatment leads to severe negative health outcomes. If correct, this means that individuals with schizophrenia have a life expectancy similar to that of Sub-Saharan Africa. Additionally, co-occurring medical conditions, such as heart disease, liver disease, and diabetes, contribute to the higher premature mortality rate among individuals with schizophrenia.⁹ Possible reasons for this excess early mortality are increased rates of these medical conditions and under-detection and under-treatment of them.¹⁰ Approximately half of individuals with schizophrenia have co-occurring mental and/or behavioral health disorders.¹¹ It has been estimated that more than 50% of patients with schizophrenia have another medical diagnosis.¹² Medical problems may be related to a variety of factors including the cognitive and behavioral impairments associated with schizophrenia itself as well as the adverse effects of the medications used in its treatment.^{13, 14} There are high rates of diabetes,^{15, 16} hyperlipidemia, obesity,¹⁷ chronic

³ Palmer BA, Pankratz VS, Bostwick JM. The lifetime risk of suicide in schizophrenia: A reexamination. *Arch Gen Psychiatry*. 2005;62(3):247-253. doi:10.1001/archpsyc.62.3.247

⁴ Breier a, Schreiber JL, Dyer J, Pickar D. National Institute of Mental Health longitudinal study of chronic schizophrenia. Prognosis and predictors of outcome. *Arch Gen Psychiatry*. 1991;48(3):239-246. doi:10.1001/archpsyc.1991.01810270051007

⁵ Roy A. Depression, attempted suicide, and suicide in patients with chronic schizophrenia. *Psychiatr Clin North Am*. 1986;9(1):193-206. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med2&NEWS=N&AN=2421271>.

⁶ Tiihonen J, Wahlbeck K, Lönnqvist J, et al. Effectiveness of antipsychotic treatments in a nationwide cohort of patients in community care after first hospitalisation due to schizophrenia and schizoaffective disorder: Observational follow-up study. *Br Med J*. 2006;333(7561):224-227. doi:10.1136/bmj.38881.382755.2F

⁷ Bastiaansen MCM, Brunia CHM. Anticipatory attention: An event-related desynchronization approach. In: *International Journal of Psychophysiology*. Vol 43.; 2001:91-107. doi:10.1016/S0167-8760(01)00181-7

⁸ Folsom D, Jeste D V. Schizophrenia in homeless persons: a systematic review of the literature. *Acta Psychiatr Scand*. 2002;105(0001-690X (Print)):404-413.

⁹ Olfson M, Gerhard T, Huang C, Crystal S, Stroup TS. Premature Mortality Among Adults With Schizophrenia in the United States. *JAMA Psychiatry*. 2015 Dec;72(12):1172-81. PMID: 26509694

¹⁰ Laursen TM, Nordentoft M, Mortensen PB. Excess early mortality in schizophrenia. *Annu Rev Clin Psychol*. 2014;10:425-48. PMID: 24313570

¹¹ Tsai J, Rosenheck RA. Psychiatric comorbidity among adults with schizophrenia: a latent class analysis. *Psychiatry Res*. 2013 Nov 30;210(1):16-20. PMID: 23726869

¹² Mitchell AJ, Malone D. Physical health and schizophrenia. *Curr Opin Psychiatry*. 2006;19(4):432-437. [PubMed]

¹³ Goldman LS. Medical illness in patients with schizophrenia. *J Clin Psychiatry*. 1999;60(S21):10-15. [PubMed]

¹⁴ Sokal J, Messias E, Dickerson FB, Kreyenbuhl J, Brown CH, Goldberg RW, Dixon LB. Comorbidity of medical illnesses among adults with serious mental illness who are receiving community psychiatric services. *J Nerv Ment Dis*. 2004;192:421-427. [PubMed]

¹⁵ Dixon L, Postrado L, Delahanty J, Fischer PJ, Lehman A. The association of medical comorbidity in schizophrenia with poor physical and mental health. *J Nerv Ment Dis*. 1999;187(8):496-502. [PubMed]

¹⁶ Muir-Cochrane E. Medical co-morbidity risk factors and barriers to care for people with schizophrenia. *J Psychiatr Ment Health Nurs*. 2006;13(4):447-452. [PubMed]

¹⁷ Goff DC, Cather C, Evins AE, Henderson DC, Freudenreich O, Copeland PM, Bierer M, Duckworth K, Sacks FM. Medical morbidity and mortality in schizophrenia: guidelines for psychiatrists. *J Clin Psychiatry*. 2005;66(2):183-194. [PubMed]

obstructive pulmonary disease, cardiovascular disease (notably hypertension),¹⁸ hepatitis, and HIV infection.

In regard to tobacco use, individuals with a mental illness are twice as likely to smoke cigarettes than the regular population.¹⁹ In the schizophrenia population, this rate is particularly high, with more than 60% of schizophrenic patients being current smokers, which contributes to excessive mortality in these patients.²⁰ In addition, the literature suggests that nearly 50% of patients with schizophrenia have a co-occurring substance use disorder, most frequently alcohol and/or cannabis (at a rate about three times as high as that of the general population).²¹

Financial costs associated with schizophrenia are disproportionately high relative to other chronic mental and physical health conditions, reflecting both “direct” costs of health care as well as “indirect” costs of lost productivity, criminal justice involvement, social service needs, and other factors beyond health care.²² Despite the clearly poor clinical outcomes for individuals with schizophrenia, not much public data is specifically available.

Why Should Schizophrenia Be Included in the National Neurological Conditions Surveillance System (NNCSS)?

We have general prevalence estimates indicating that 1.2% of all Americans – roughly 3.2 million people – have schizophrenia from the National Institute of Mental Health (NIMH). Beyond that broad approximation, we just do not know much more about this patient population. In particular, if we turn to public mental health agencies, who provide the vast majority of publicly financed inpatient hospital and community-based services for people living with schizophrenia, the lack of basic data is striking. For example, baseline demographic data on gender, average age of onset, race, religious affiliation, ethnic background and income are often completely absent. That lack of information often extends to the realm of service delivery. State mental health agencies often struggle to identify the specific type of care provided, the penetration rate for mental health and related support services in a given geographic area, the intensity of service delivery for each patient with schizophrenia and, most importantly, verifiable clinical outcomes. An amendment to the National Neurological Diseases Surveillance System could begin to help answer these baseline questions.

A comparison of schizophrenia to Alzheimer’s disease and Parkinson’s disease – two disorders that unambiguously have a neurological basis – quickly makes a compelling case for schizophrenia finding its proper diagnostic home in the neurological disorders (see Table below). All three disorders share multiple features including significant brain and cognitive deterioration,

¹⁸ McCreddie RG. Scottish Schizophrenia Lifestyle Group. Diet, smoking and cardiovascular risk in people with schizophrenia: descriptive study. *Br J Psychiatry*. 2003;183:534–539. [PubMed]

¹⁹ Lasser K, Boyd JW, Woolhandler S, Himmelstein DU, McCormick D, Bor DH. Smoking and Mental Illness A Population-Based Prevalence Study. *JAMA*. 2000;284(20):2606–2610. doi:10.1001/jama.284.20.2606

²⁰ Sagud M, Mihaljević-Peles A, Mück-Seler D, Pivac N, Vuksan-Cusa B, Brataljenović T, Jakovljević M. Smoking and Schizophrenia. *Psychiatr Danub*. 2009 Sep;21(3):371-5.

²¹ Green A, Drake R, Brunette M, Noordsy D. Schizophrenia and Co-Occurring Substance Use Disorder. *Am J Psychiatry* 164:3, March 2007

²² Desai, PR, Lawson, KA, Barner, JC, Rascati, KL. Estimating the direct and indirect costs for community-dwelling patients with schizophrenia. *Journal of Pharmaceutical Health Services Research*, 2013 Jul;4(4):187-194. doi/10.1111/jphs.12027/epdf

diagnostic approach, types of treatment, having a strong genetic basis, clearly speaking to the consideration of schizophrenia as a neurological disorder (interestingly, schizophrenia appears more heritable than Parkinson's disease).

Where these disorders depart company, unfortunately, is the personal and social impact for diagnosed individuals. With a diagnosis of Alzheimer's or Parkinson's disease, the clinical paradigm of providing timely and appropriate care is robustly in place. With schizophrenia, a similar paradigm is far from guaranteed, especially in the longer term, with striking rates of patients being untreated, homeless and incarcerated. Thus, while schizophrenia appears to legitimately deserve consideration as a neurological disorder based on clinical and scientific grounds, the lack of recognition of this reality has sadly been associated with much suffering, debilitation and public health cost.

Hiding in Plain Sight: Is Schizophrenia Not *Already* a Neurological Illness/Disease?

Some may ask – why is this even a question? Depending on the audience, it may not actually be a question. The defining feature of schizophrenia is psychosis, manifested primarily by delusions and hallucinations. Psychosis is not only associated with schizophrenia but also dementia, Parkinson's disease, stroke, brain tumors, and the use of drugs or alcohol. With such clear associations with brain-based processes, it would seem clear that schizophrenia-related psychosis is also rooted in the brain. In the mental health treatment context, it is a no-brainer, so to speak – of course it is a brain disease! It is no more a question that it arises from disturbances in brain function than one questions whether Parkinson's disease or epilepsy arises from the brain.

In the clinic, or even more poignantly, in a psychiatric inpatient unit or emergency room, a patient with severe auditory hallucinations or delusions is excused from any immediate responsibility or culpability for their symptoms. The symptoms are not simply a 'behavioral problem' – rather, any clinician with experience treating schizophrenia will recognize how a patient's thoughts, emotions and behavior have been hijacked by a process that is beyond their control. Historically, the 'hijacker' may have been assumed to be the result of a demon or spirit (c.f. epilepsy which, historically, was attributed to demonic possession), or poor parenting; in the modern day, there is no question that it is a neurological process.

Stepping from the clinic and into the lab, one will find assumptions regarding the biological basis of schizophrenia even more firmly ensconced. We are well beyond what are now considered quaint notions of the 'schizophrenogenic mother' or psychosis as a social construction, and questions regarding the biological basis of schizophrenia have long since moved from 'if' to 'how'. A plethora of genetic, post-mortem and neuroimaging studies have demonstrated clear evidence of the biological underpinnings. Perhaps one of the more simple, compelling facts that undergirds the biology argument is heritability and twin concordance: if one of an identical twin pair has schizophrenia, the other will have a 50% chance of also having schizophrenia, even if raised in a different environment. This number is comparable to that for Alzheimer's disease and

greater than that for Parkinson's disease.^{23, 24, 25}

If schizophrenia having a neurological basis is such an obvious given for clinicians and scientists – people that are 'in the know' – why does this question remain in the general public? The answer is likely to be a complex mix of factors that includes a lack of proper education of the public and historical inertia in the systems of care that cater to the schizophrenia population (e.g. psychiatry vs. neurology), as well as how this care is paid for (e.g. structure of reimbursement codes by Centers for Medicare and Medicaid Services).

Whatever the reasons for the disconnect between established clinical/scientific knowledge regarding schizophrenia and the inadequacies in the systems of care for the illness, there is utmost urgency in bridging this gap. As outlined above, for many individuals with schizophrenia it is *literally a matter of life and death*. We believe that re-classifying schizophrenia formally as a neurological disease will be an important first step for this urgent priority.

We believe that the inclusion of schizophrenia in the NNCSS could be an important first step towards understanding schizophrenia better, reducing stigma in the illness, and re-invigorating our orientation towards timely and appropriate treatment as well as making incarceration and homelessness unacceptable outcomes for schizophrenia. We appreciate the chance to provide our recommendations to you on this matter. We are happy to provide any additional information or comments that you may require.

Regards,



Linda Stalters, MSN, APRN (ret)
Chief Executive Officer & Founder
Schizophrenia And Related Disorders Alliance of America



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Chair of the Board of Directors
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²³ Gejman P V., Sanders AR, Duan J. The role of genetics in the etiology of schizophrenia. *Psychiatr Clin North Am.* 2010;33(1):35-66. doi:10.1016/j.psc.2009.12.003

²⁴ Gatz M, Reynolds CA, Fratiglioni L, et al. Role of genes and environments for explaining Alzheimer disease. *Arch Gen Psychiatry.* 2006;63(2):168-174. doi:10.1001/archpsyc.63.2.168

²⁵ Wirdefeldt K, Gatz M, Reynolds CA, Prescott CA, Pedersen NL. Heritability of Parkinson disease in Swedish twins: A longitudinal study. *Neurobiol Aging.* 2011;32(10). doi:10.1016/j.neurobiolaging.2011.02.017

	Schizophrenia	Alzheimer's Disease	Parkinson's Disease
Brain and Cognitive System Disturbances			
Cognitive	✓	✓	✓
Affective/Motivation	✓	✓	✓
Social	✓	✓	✓
Sensory and Motor	✓	✓	✓
Brain Structural Changes	✓	✓	✓
Brain Functional Changes	✓	✓	✓
Genetics			
Heritability	~80%	~80%	~35%
Monozygotic twin Concordance	~50%	~50%	~10%
Diagnosis is Clinical (no definitive lab test)	✓	✓	✓
Psychotropic Medications Mainstay of Treatment	✓	✓	✓
Research Approaches Include Cognitive, Neuroimaging, Electrophysiology, Genetic, Molecular, Cellular	✓	✓	✓
Poor Access to Care	40% Untreated ²⁶	Negligible	Negligible
Homelessness	6% Patients Homeless ²⁷ 11% Homeless have Schizophrenia ²⁸	Negligible	Negligible
Incarceration	15% State Prisoners and 24% Jail Inmates Have Psychosis ²⁹	Negligible	Negligible

¹ About 50 percent of individuals with severe psychiatric disorders. <https://mentalillnesspolicy.org/consequences/percentage-mentally-ill-untreated.html>.

¹ Schizophrenia Facts and Statistics. <http://www.schizophrenia.com/szfacts.htm>.

¹ Folsom D, Jeste D V. Schizophrenia in homeless persons: a systematic review of the literature. *Acta PsychiatrScand.* 2002;105(0001-690X (Print)):404-413.

¹ James DJ, Glaze LE. *Mental Health Problems of Prison and Jail Inmates.*; 2006. Retrieved from <https://www.bjs.gov/content/pub/pdf/mhppji.pdf>

²⁶ About 50 percent of individuals with severe psychiatric disorders. <https://mentalillnesspolicy.org/consequences/percentage-mentally-ill-untreated.html>.

²⁷ Schizophrenia Facts and Statistics. <http://www.schizophrenia.com/szfacts.htm>.

²⁸ Folsom D, Jeste D V. Schizophrenia in homeless persons: a systematic review of the literature. *Acta PsychiatrScand.* 2002;105(0001-690X (Print)):404-413.

²⁹ James DJ, Glaze LE. *Mental Health Problems of Prison and Jail Inmates.*; 2006. Retrieved from <https://www.bjs.gov/content/pub/pdf/mhppji.pdf>