Tuberculosis (TB) was once popularly depicted and even glamorized in art, especially among European literary figures, painters, and artists. Today any glamor is replaced with stigma of infection, contagiousness, poverty, malnutrition, and HIV infection. Stigma generally leads to isolation with attendant psychological, social, and economic costs, and some studies report it may contribute to delays in TB diagnosis and treatment, especially when the presence of health workers at a person’s home to administer direct observational therapy (DOT) might reveal their infection status to neighbors or community members closely.

The visual artist Paulina Siniatkina uses her personal experience and art to fight the stigma of TB. In 2015 she spent 7 months in a TB clinic in Moscow. For the first 3 months she was not permitted to leave. Isolation from family and friends was difficult, as was finding motivation and meaningful activities. She was afraid and was advised by a physician not to tell anyone she contracted TB at the risk of being “branded for life”; she “thought it [was] shameful to have TB...so, [she] kept silent,” and soon learned that others in the clinic experienced the same feelings of isolation and stigma.

The experience inspired Siniatkina, a professional artist prior to her TB diagnosis, to shift the focus of her art to the disease. Previously she had studied the Renaissance masters and was influenced by artists such as Antonio del Pollaiuolo and the Netherlandish painter Petrus Christus. Following her diagnosis, Siniatkina’s style evolved, forged by her experience with the infection. “As long as people are afraid to talk about [TB, the] disease will continue to spread,” she said, adding, “I realized that I want(ed) to fight TB and the only weapon I can use is art.” She began painting portraits of fellow residents in the clinic. Her images, compiled into a 2016 series called Hold Your Breath, have been shown in several Russian and European cities and exhibited at the World Health Organization headquarters in Geneva on World TB Day (March 24) in 2017.

Her portrayals from the series are authentic and reveal the faces, spaces, and bodies of people living with TB and its stigma. In the life-sized painting Zhanna, for example, the viewer is invited into an intimate space—the patient on her bed at a level of closeness forbidden when TB is contagious, her eyes directed at her viewers, who in turn are compelled to return the gaze and see her.

Familiar, comfortable imagery (a flowered bedspread, the sitter’s casual position) join medical elements (a bottle of pills and medical trapeze) to reflect the tension of living an ordinary life within clinic walls. Empty space behind and around the patient signals the deprivation of clinical environments, the idle time-space of quarantine, and a social void—the loss of connection with friends, family, and personal identity.

Zhanna, tempera on canvas, 100 × 105 cm.
Reprinted with permission from Paulina Siniatkina, copyright 2016.
Siniatkina has taken up themes of health and illness in subsequent series. In a 2018 You Don’t Want to Hear This collection, Siniatkina created a series of video monologues of people treated for TB and other illnesses with stigma (eg, bipolar disorder, HIV), the first time the individuals discussed their illness publicly. In her 2019 Diagnoses series, paintings of chest x-rays become a metaphor for “seeing inside” not only the body but the psyche; with TB, she says, there is a “war inside of you,” physically and metaphorically making it difficult to accept one’s own body and identity.

And in Siniatkina’s 2019 What Do You See? series depicting persons infected with TB wearing masks, Siniatkina poses the question: Are you seeing the person for who they are? For their personality? Or for the disease?

It has not escaped her attention that her artwork is now at risk of being misinterpreted as a response to the COVID-19 pandemic. Masks were often her visual symbol for TB; now, with mask-wearing largely destigmatized, her advocacy is obscured, and her work to make visible the TB community’s plight has been overshadowed, giving the artist herself a feeling of fragmentation and loss of self-reliance. Feeling disjointed and yet again misunderstood, she painted a part of her body each week in the first year of the pandemic to rediscover love for her body piece-by-piece, and to establish a new sense of self as someone with TB living during the outbreak. Her vision is that individual collectors will buy each piece, reassembling her “body” for a show, In Pieces—the work and title a metaphor for the dysmorphophobia and identity confusion people with chronic illness cope with regularly.

Siniatkina’s work can remind physicians and health care workers that patients are individuals with a singular experience navigating their diagnosis and illness. And, in a recent interview, she challenges how the medical community prioritizes disease management, reminding us that TB is still a worldwide killer. With COVID-19, she said, “It’s almost like there are no other diseases anymore.” TB continues to kill more than 1.4 million people per year, and the perceptions around the disease continue to perpetuate stigma and secrecy.

Siniatkina wonders what would be possible if medical communities sought a cure for TB as vigorously as they seek interventions to manage COVID-19.

Siniatkina’s work invites us to pause—her titles call us to breathe, to hear, and to see the faces and stories behind TB. As an activist, Siniatkina uses her art to help people with TB speak openly about their disease. It is her hope that open communication about TB will help others understand the disease, and ultimately slow TB’s spread.