UMass Mind Network Newsletter



RECOVERY ABOVE ALL ELSE: THE ROAD TO HEALING FROM A DIAGNOSIS AN INTERVIEW WITH JC ABOUT HER ROAD TO RECOVERY

BY EMILY HUANG

For many people, receiving a mental illness diagnosis is a life changing event and can feel lifedefining. Oftentimes, fear of the unknown can cloud over hope, healing, and joy. But it was the striving towards those very states, or even the possibility of them, that helped pave JC's path to recovery.

In a powerful memoir essay submitted to UMass Mind, JC documents her experience of working hard to prioritize recovery above all else after receiving a diagnosis of schizophrenia—a component of the patient journey that can be overshadowed by the diagnosis itself, and something that is challenging to do in the face of stigma and isolation.

UMass Mind members Brenna Chuang and Emily Huang sat down with JC to talk more with her about the theme of recovery, and how she was able to strive toward this goal. In her interview with us, JC reflected, "Making sure you're not in denial is the first step, and then taking real, small but important steps towards recovery, however that might look like." For JC, a significant aspect of being able to achieve this was to lend oneself understanding and compassion. She advised, "Try to get to know yourself and just be accepting of your symptoms and how you are, and just try to understand how you're having a hard time functioning... You have to understand that [the doctors] are addressing something that's about you that is problematic, not because you're a problem in and of yourself. So you have to accept it, but you also can believe that you can get better and change."

Undergoing a significant mindset change is never an easy task, especially while also navigating a diagnosis and all of the external perceptions, prospects, and emotions attached to it. On one's own, it can become overwhelming. JC emphasized how crucial it was for her to have social support throughout her journey, which helped her feel loved and encouraged without judgment as she focused on recovery. In particular, JC referenced her partner and mother, both of whom she described as being understanding of her struggles and open to working with her to get better. JC noted, "[My partner] doesn't put pressure on me to be a certain

way, but sees that I am really trying to build up my life and make it productive." She underscored the importance of loved ones meeting her where she was, rather than imposing expectations that would have been confusing and detrimental to recovery.

Another cornerstone in JC's social support was her team of doctors, particularly Dr. Fan, whom JC mentioned as being a "steady touch point" throughout her treatment. JC emphasized the importance of being able to communicate with her team without fear. "I know they're there to help me," said JC. "I don't see them as any sort of threat or any danger, or anything like that, but to understand that they're really there with my best interests in mind."

Even surrounded by resources, loved ones, and healthcare providers, the road to recovery may feel long. Reflecting on how she was able to embark on and commit to her own journey, JC remarked, "A big part of it was always having some sort of... underlying belief that I had so much more to offer than just being a diagnosis." She continued, "I never really saw myself as a victim, because I did have enough self-confidence and underlying assurance in myself that I knew I would get better."

Even though JC's personal experience was with schizophrenia, she believes that the act of striving towards recovery and well-being is something universally applicable. JC concluded, "I think everyone has an obligation to look after their mental health, but it really just means taking care of yourself, and carving out the best possible life you can have for yourself, and shining and lending your light to the world."

Note: For the purpose of maintaining the anonymity of the interviewee, we have used a pseudonym to refer to them.

Click <u>here</u> to watch the full interview!



PRESCRIBING FOOD AS MEDICINE IN THE REAL WORLD: SPOTLIGHT ON UMASS MEDICAL STUDENTS LEADING THE UMASS MIND NUTRITION PROGRAM

BY ALIX BARRY

As UMass Mind begins its third iteration of our Nutrition Program, this time at Massasoit Road House, we wanted to spotlight the medical student leaders responsible for implementing the program. Medical students are an essential part of our Community Intervention Program. They help create and execute projects aimed at improving the quality of life of those with serious mental illness (SMI) within the Worcester community.

Aviv Liani is passionate about nutrition education recognizes and its importance for vulnerable populations. She joined UMass Mind to "contribute to а program that provides accessible and nutrition hands-on



education in people's communities to address knowledge gaps and barriers to health." Aviv has formed personal relationships with program participants and has watched their interest in nutrition and cooking grow throughout the program. She believes accessible nutrition education should be implemented as part of a holistic healthcare plan for everyone. Moving forward, Aviv hopes to continue delivering an interactive nutrition curriculum throughout the Worcester area, tailored to address specific needs and challenges of community members.

Prashasti Upadhyay joined UMass Mind because it offers a unique opportunity to participate in impactful research studies while serving the community and patients she aspires to work with. Prashasti enjoys going into the community and interacting face-to-face with patients, hearing realtime feedback on improving the program, and incorporating what they need and want to see. Prashasti believes that considering the community's needs when designing research programs is crucial. When speaking of her involvement in the Nutrition Program, she shared, "One of the most interesting aspects of this project is how food brings people together. At the end of each session, our team educates the participants on health and well-being. Afterward, we get to share a meal at the heart of human communication, relationships, and bonding."



Madison Mixer. а student pursuing the Population-Based Urban and Rural Community Health Track, became involved UMass in Mind by chance. "I have always loved cooking, so when I received an email from

the first-year class, I signed up to volunteer to help cook in one of the healthy living iterations and loved it! I kept attending those sessions and then decided to help run the next iteration." She has found the experience to be helpful in learning to talk about healthy eating and cooking, as well as creating relationships with participants. Her favorite parts of the Nutrition Program include the MyPlate lesson, which discusses how to build a nutritious and balanced meal containing multiple food groups, as well as the mindful eating exercises that help participants reflect on their reasons for eating and how eating makes them feel. Madison feels that the program is a great opportunity to learn and practice discussing and incorporating food as medicine in connection with both physical and mental health. Since running the Nutrition Program, Madison feels more capable of caring for herself and counseling her patients on making healthy changes in the future.

The Nutrition Program is just one piece of UMass Mind's Community Intervention Program, which aims to encourage healthy food choices and eating habits, increase physical activity and exercise, address co-occurring substance use in individuals with SMI, and help them build support systems to establish healthy lifestyle changes via recovery and support-based discussions. The Nutrition Program in particular is tailored to meet the specific needs of the people we work with to provide the most relevant nutrition and lifestyle education in an accessible format.

Click <u>here</u> to watch a video about our Nutrition Program!



COMBINING MINDFULNESS AND VISUAL ART: ZENTANGLE AS A NOVEL INTERVENTION FOR INDIVIDUALS WITH SERIOUS MENTAL ILLNESS BY BRENNA CHUANG

Individuals with serious mental illness (SMI) often experience symptoms that impair their daily functioning. While medication and "talk therapy" are the current conventional approaches to treatment, creative art interventions have been gaining traction as complementary treatments.



Zentangle is a mindfulness-based art form that emphasizes mindful practices and non-verbal self-expression, through the design and completion of "tiles," an art technique that involves creating patterns on a small paper rectangle. Mindfulness is the practice of focusing on what an individual is experiencing in the moment. The art form offers an outlet to express inner feelings and experiences without requiring verbal articulation, opening a new avenue for individuals with SMI to communicate with others. Additionally, Zentangle aims to foster greater levels of self-confidence in those who participate in the art as well as appreciation of their ability to create art. In collaboration with the Zentangle Foundation, UMass Mind conducted a pilot study exploring Zentangle as an adjunct treatment for individuals with SMI. The findings from the study were recently published in <u>Frontiers in Psychiatry</u>

This pilot study took place over the course of 8 weeks through weekly 90-minute virtual sessions. Participants displayed a significant reduction in psychiatric symptoms and a significant increase in mindful attention.

Participants engaged in a focus group following the study where they shared their experiences and provided feedback on the program. Four central themes were identified: Achieving mindfulness through Zentangle; the power of uncomplicated art creation; understanding the value of self-appreciation; and fostering a positive environment during the COVID-19 pandemic. One participant noted, "you're actually drawing while you're doing (mindfulness)". Another participant shared insight into how they were able to experience more self-appreciation, remarking, "With depression, you can't feel grateful... But this one (Zentangle) feels a little bit like easier, because you're actually like feeling gratitude in that minute for what you're doing."

UMass Mind plans to continue exploring creative arts interventions, such as Zentangle, to help combat the challenges experienced by individuals with SMI.

AN INTERVIEW WITH ZENTANGLE FOUNDERS RICK AND MARIA: HOW AN IDEA SPREAD ACROSS THE GLOBE



In 2022, UMass Mind had the opportunity to interview Zentangle founders, Rick and Maria, about the art form and its potential as a mindfulness-based intervention for mental health. During the interview, Rick and Maria discussed the origins of Zentangle and how it became what it is today. There are trained Zentangle instructors around the globe. To hear more about Zentangle and its benefits from its founders click <u>here</u> to watch the full interview!

PEER SPECIALIST JOB OPPORTUNITY!

CURRENT STUDIES: ACTIVELY RECRUITING!

Study #1: Metabolic Benefits of Adjunctive Lumateperone Treatment in Clozapine-treated **Patients with Schizophrenia**

The purpose of this investigator-initiated, double-blind, randomized, placebo-controlled study is to determine whether adjunctive lumateperone (Caplyta®) might improve metabolic health in clozapine-treated individuals with schizophrenia. Lumateperone is an FDA-approved medication for adults with schizophrenia. Patients will receive lumateperone or placebo for 12 weeks and meet with the study team approximately 8 times. A variety of metabolic outcomes will be measured, including body fat distribution using a body composition analyzer and lipid particle size using NMR spectroscopy. For a brochure of the study, please click here. IRB Docket # STUDY0001339

Study #2: A Prospective Multi-center Study to Characterize the Natural History of Tardive Dyskinesia (TD) and Investigate the Real-world Effectiveness of Deutetrabenazine on the **Multi-dimensional Impact of TD**

The purpose of this study is to observe the real-world course of TD and evaluate the effectiveness of deutetrabenazine (AUSTEDO®), an FDA-approved medication, on TD. This is an observational study, meaning that if the medication is prescribed, it will be by the patient's regular healthcare provider as part of their routine clinical treatment. Patients who experience at least mild TD symptoms, whether or not already on medication treatment for TD, are eligible for the study. Patients will meet with the study staff every 1-3 months over the course of 3 years. The study visits can be in-person or remote. For a brochure of the study, please click <u>here</u>. IRB Docket # STUDY0001020

Our studies are conducted at 26 Queen Street, Worcester, MA 01610. You will be compensated for your time being involved in any study. If you are interested or would like more information about any of our studies, please call 508-856-MIND (6463) or email MIND@umassmed.edu

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