

The Edward & Mott Moore Awards

BY JEN CASASANTA



Layperson Award Winner: Mary Tantillo, PhD

Dr. Mary Tantillo and I met at Finger Lakes Coffee Roasters in Pittsford, NY soon after she had arrived back to Rochester after her trip to Washington DC for the Academy of Eating Disorders 30th Anniversary Conference. It was a fitting location since she spent much of her time there working and writing her recently released book, "Multifamily Therapy Group for Young Adults with Anorexia Nervosa: Reconnecting for Recovery." She created this book to reframe the illness and was excited to finally be able to present this to her colleagues in person since it was launched during the pandemic. The basic concept is groundbreaking and combines the principles of motivational interviewing with relational-cultural theory. "We grow through connection. Recovery happens because of the quality of relationships with close others," she believes. She goes on to explain that eating disorders are 'diseases of disconnection'. This new approach doesn't blame the family or patient and instead, blames the illness. The illness creates a burden and distress for the patient and family, so treatment is about getting the person connected with themselves (their genuine thoughts, feelings, values and needs) and their support system.

Eating disorders (ED's) have the second highest mortality rate of all mental health disorders, surpassed only by opioid addiction.¹ Anorexia has an estimated mortality rate of around 10% and among those, 1 in 5 deaths is by suicide.² "There are a lot of myths about eating disorders. Many

still believe that it's a skinny, rich, white girl's disease but that isn't true. Any one of us could have an eating disorder. Different sizes, shapes, colors, sexual-orientation, genders. In fact, people who are transgender and LGBTQIA are at very high risk. Sure, a lot of eating disorders happen to females but things like binge eating? That is more evenly distributed among men and woman – 40% and 60% respectively." She goes on to say that even athletes can be susceptible. In fact, being a good athlete is a hallmark of what can get you into an eating disorder: perfectionism, achievement, working hard. "Their strengths can get twisted by the illness which is why coaches and athletic trainers need to understand how to identify an eating disorder. It's a sports injury. If you broke your leg, you wouldn't be playing. If you have an eating disorder, you can't play until you get more stabilized," she explains.

Dr. Tantillo is very passionate about the relational/motivational form of treatment for ED's. In fact, she would consider this to be her most meaningful professional accomplishment. She uses this model at the Western NY Comprehensive Care Center for ED's (WNYCCCED's), Project ECHO training of schools and providers and The Healing Connection. The Healing Connection is the eating disorder facility she founded in 2010 to assist in treatment for ED's. "Creating a continuum of care in Western NY using that model, conducting research, and writing the book regarding multifamily therapy group to teach others about

that model, has all meant a great deal to me. I feel like I, in partnership with my colleagues and individuals with lived experience have been able to make a difference in the lives of patients, families, our community and beyond, by sharing the model ...” she says.

When you hear Dr. Tantillo speak so enthusiastically about her life’s work you might wonder what her path looked like. When she was young, she wanted to be a priest but discovered quickly that it wouldn’t be possible in Roman Catholicism. She searched for ways to help people spiritually, in a holistic, biopsychosocial way. “How could I carry out a ministry and be a vehicle of The Spirit, that would serve others? Psyche is the human soul, mind or spirit and Nursing is attentive to the whole ‘person’ of the patient, as well as the environment that promotes the healing of the patient. Psychiatric nursing became my calling,” she says. Taking care of individuals with ED’s and their families became her ministry where

she could pay it forward to others. She also wanted to make changes in women’s health and at the time she initially trained as a nurse, ED’s were believed to be occurring only in girls and women. She would watch the inpatients’ responses to the treatments offered to them, but they often did not understand the rationale for the treatments or fully benefit from them. “While treatments were cognitive, behavioral, or psychodynamic in nature, what was missing was the emphasis on growth of the self-in-relationships with others. I wanted to change that,” she says. For ten years she traveled every summer to Wellesley College’s Stone Center (aka: Jean Baker Miller Training Institute/ International Center for Growth in Connection) to train in relational-cultural theory and therapy. “That was the missing piece. I was raised professionally in the setting of URM’s biopsychosocial model and the U of R School of Nursing’s unification model, where a nursing scholar is involved in clinical practice, education, and research,” she says.

Dr. Tantillo started her studies with an associate degree in nursing from Monroe Community College followed by a bachelor’s degree in nursing from Nazareth College. “My mom worked in mental health in community group home settings, and when I was a teen and college age student, I remember sitting down to dinner with group home residents sometimes. I loved the sense of community there and felt that community, connection, purpose, and belonging were essential for growth and healing,” she says. This is why she specialized in group therapy and studied family-based treatments – and ultimately created this new way to conduct the Multifamily Therapy Group.

She went on to earn her master’s degree in nursing with

a specialization as a Psychiatric Mental Health Clinical Nurse Specialist, following that with her PhD in nursing from Adelphi University. She flew there each Friday for over three years for training in qualitative and quantitative research. From 1982 through 1999 she held numerous positions at the University of Rochester, including as inpatient nurse, nurse manager, nurse educator and Administrative Director of Ambulatory Services, then Director of the Eating Disorders Treatment Service. In 2000, with changes happening at the hospital and the support of Jack McIntyre, MD, she was able to move the clinical program serving patients to St. Mary’s Hospital (aka: Unity Health). She also became a fellow for the Academy of Eating Disorders in 2003. While at St. Mary’s in 2005, she became Director of the Western NY Comprehensive Care Center for Eating Disorders (WNYCCCED). In 2008, another shift occurred and the WNYCCCED moved to the U of R School of Nursing and in 2010 she moved the clinical program to create the previously mentioned, Healing Connection. She opened it on Martin Luther King Day because it signified finally being able to create a home where the staff and she were free to offer the kind of care patients with EDs and their families needed and deserved.

“I was always interested in patient and family needs but also the systems of care serving them in the community and the ways to prevent and intervene early to prevent full-blown illness. I felt compelled to change the treatment of eating disorders and to create a home in the community wherein we could offer that treatment to patients and families while teaching the model to others and researching the effectiveness of what we were offering,” she states.

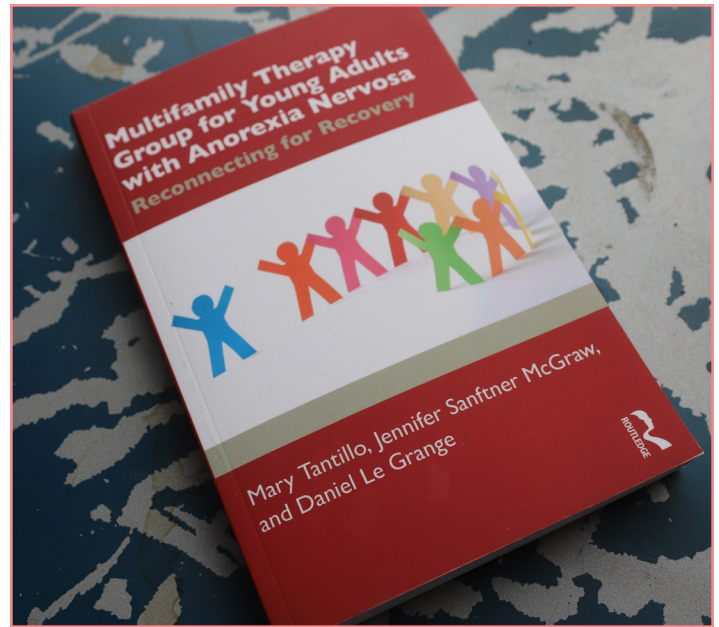
In 2013 she was promoted to Professor of Clinical Nursing at the University of Rochester School of Nursing and a Clinical Professor in the Department of Psychiatry at the University of Rochester School of Medicine. In 2017 she worked with WNYCCCED leadership and staff to launch the first Project ECHO for eating disorders in the world. It is a tele-mentoring, tele-education approach for primary care, behavioral health care and college health care practitioners and students using the Zoom platform. By 2018 they launched the first school-based Project ECHO for eating disorders in the world for grades K-12 school personnel. They serve the 30 counties in Western and Central NY but also have providers Zooming in from other states. In 2019 she completed a pilot study of the multifamily therapy group for young adults with Anorexia Nervosa which ultimately led to a publication in the International Journal of Eating Disorders and her book in 2021.

The thing she is most proud of is helping her patients and families. Through writing her treatment manual, founding The Healing Connection and directing the WNYCCCED she has been able to ensure the full continuum of care for patients and families. These relationships go both ways though. When asked who her biggest influences have been, her first response is them. “Patients and families have taught me more than any book or journal article, or theory could teach me.

They taught me how to be in a relationship with them so I can help them do scary things to combat the ED." She credits her husband, Dr. Odysseus Adamides, son, Eddie Adamides, stepkids, Katie and Paul Adamides, mom, Connie Tantillo, and siblings Chris, Mark, Stephen and David for helping her to try to be the best version of herself, especially with work ethic, understanding human nature and being forgiving and compassionate toward others. Academically, she thanks her mentors, Dr. Susan McDaniel and Dr. Harriet Kitzman, her research colleagues, Dr. Jennifer Sanftner McGraw and Dr. Daniel Le Grange, as well as the pioneer of relational-cultural theory, Dr. Jean Baker Miller. Additionally, she is grateful for her many friends including Dr. Ann Griep (long-time champion of quality care for patients with eating disorders) and colleague of almost 40 years, Dr. Richard Kreipe, who also happened to be her nominator and submitted the most thorough EMM Award packet ever received by MCMS.

With such a diverse background in healthcare, we asked what she believes is the biggest challenge the healthcare community is facing. Her response is, "Siloed healthcare and the lack of understanding of the social determinants of health. We focus on what we are doing at the bedside without reflecting on how our work with the patients and families is only one piece of a trajectory or journey and we do not always help them to prepare for that... They need a healthcare team that is educated and practices in a truly interprofessional way. Treatment team members need to understand each other's roles and the gifts we all bring to the treatment table," she says. An example is that the WNYCCED offers a continuum of care comprised of their staff as well as those from The Health Connection and Golisano Children's Hospital. Some of these staff are located across each setting and in the community. "We have figured out a way to truly integrate medical and psychiatric care and ensure continuity across agencies," she says. Another example is that for over 10 years she conducted a yearly ED Seminar for psychiatric residents at the URM and Rochester Regional Health along with trainees from other disciplines. She purposely taught that seminar with leadership from other disciplines and included individuals and family members with lived experience as co-facilitators. "We create a full treatment team at the seminar to model this for the trainees and use an interprofessional approach to learning. We each need to consider how we fit into the big picture of health care in our community and work with each other across organizational boundaries to consider big picture needs while providing quality care to individual patients and families," she says.

From this very full list of experiences, you can see her enthusiasm for her work is contagious. One of the



biggest challenges she has found with this sort of eagerness is the need to temper her expectations. "I want a lot for patients and families in our community and it can't happen all at once and I need to remember I don't have to be responsible for making it happen alone. Building and rebuilding a continuum of care for patients and families three times has been challenging and rewarding," she smiles. Her most recent challenge has been collaborating with others to establish the upstate adolescent ED residential facility in Pittsford during a pandemic and the aftermath. She did establish the Healing Connection during the recession of 2008-2009. "I should not be surprised! The things that matter the most to us are often the things that require a lot of work," she laughs. In fact, the biggest lesson she has learned this year is to pace herself and accept help when the going gets tough. "I have learned that more is not always better... Sometimes you must let go of things or move back a few steps to move forward. That has been a tough lesson when I feel compelled to keep moving forward. Change is not linear. It is back and forth, with things evolving over time," she says.

Next on her agenda is to share the multifamily therapy group model and conduct more research about it. She wants to debunk ED myths and increase education so everyone in the community understands that anyone can develop an ED and providers won't feel frightened or deskilled in the face of an ED. Dr. Tantillo plans to continue to grow Project ECHO and other virtual educational offerings via WNYCCED, as well as continue to support growth of The Healing Connection.

Both inside and outside of work she tries to live by the 3 M's: mutuality, mindfulness and motivation. She is joyous and open and finds her inspiration everywhere. "God has been my wellspring. Especially in the form of the Spirit which lives and moves in each of us. Illness, like EDs and trauma, can make us forget this. It can leave us feeling unworthy and forgetting that there are others out there who care and value us. My goal

in life is to be a medium or channel for that Spirit which makes all things whole...for individuals and families, as well as communities... "she says.

Though she works hard, she isn't all about work. In fact, if you happen to see her at an event with a dance floor, she will likely be the first one on it and the last one to leave. "I blew out my knee dancing at a conference when I slid into the center of the dance floor while pretending to play the electric guitar like a rock star. I think it was either a favorite Aerosmith or Journey song. It was amazing – until the next day – Ah! My 16-year-old spirited self has trouble believing it is in the body of an older person," she laughs. Outside of dancing, she really loves spending time in the water and the woods. Her ideal day would be driving her bike down the canal path on a sunny, summer, blue sky day or being in the warm glow of the sun with family and friends at a beach. "I have told God these experiences would be great ones for me in the next life (if I get to choose!)," she laughs.

She leaves us with these closing thoughts. "We grow in and through connection. I would not be receiving this Edward Mott Moore award today if it were not for my family, friends, colleagues, patients, and their families, not to mention the grace of God. I am so grateful to be considered someone who emulates Dr. Edward Mott Moore - an exemplary practitioner, teacher, investigator, leader, and community activist."

Now everyone else will know what her friends and loved ones have known for many years. She's an inspiration, with a sharp mind, kind heart and loads of energy to spare. There's something about Mary...

References:

1 Chesney, E., Goodwin, G. M., & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry, 13*(2), 153-160.

2 Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with Anorexia Nervosa and other eating disorders. *Archives of General Psychiatry, 68*(7), 724-731.