

A CONVERSATION SERIES: EATING DISORDERS IN ADULT WOMEN



Mary Tantillo, PhD, PMHCNS-BC, FAED, Margo Maine, PhD, FAED and Karen Samuels, PhD talked about their passion in treating adult women and the complex developmental stressors and unique treatment approaches that should be taken into consideration when working with mature women. Interviewed by Ibbits Newhall

“There’s a special place in hell for women that don’t help other women” – Madelyn Albright

Ibbits: One of the quotes I really loved in the article was “the paradox emerges: a life threatening illness becomes a means of coping with the complexities and dilemmas of the aging process.” One of the questions I wanted to start with is, besides having been in the field for many years and being women of a certain age, was there a particular series of events or tipping point either in an individual you were treating or a sequence of women coming through your door that really prompted your passion and interest in working with this population?

Margo: A couple of things come to mind – the first influence that sparked my burgeoning interest in working with adult women was when I started receiving calls from mothers of former patients. During their daughter’s treatment, I would think “the mom has had some issues” or mention their dieting as a concern. But these were families where neither parent would admit there was a problem. Five to eight years later, the mom would be calling for help herself. That was my first, “hmm there might be something here!” I realized there was something going on. But the experience that started me writing about adult women and traveling across the country and world to talk about eating disorders in adult women was when a woman in her early forties came in to see me. She had been disordered in her eating since age twelve when her parents brought her to Weight Watchers. She later developed anorexia, and got better on her own but after having her two children, became severely bulimic and had been bulimic for quite a few years before she came to me. She was deeply ashamed when she realized she had an eating disorder. She was one of those perfect women who everyone thinks has everything. She loved when people said she looked like a Barbie doll. The idea of her accessing help was very difficult for her so she decided to go to the person she could trust – her OB/GYN. She *knew* the nurses would say things about her weight loss. She had lost twenty pounds in the last year through an increase of her bulimia symptoms, a decrease in her eating, and crazy, crazy amount of exercise. She was prepared for the nurses and staff in the office to say how “great” she looked but what she *wasn’t* prepared for was when the physician walked into the examining room and said “how does your husband like your new body?”

Mary: Oh my.

Ibbits: And here she was looking for someone to tell her what to do, to help her.

Margo : And this was the person she trusted. So, of course, she didn’t tell him but walked out of the office and was so depressed; she thought she might die from her illness. It took a couple of weeks but she went on the internet and found my name. That’s why I wrote “The Body Myth”! (*laughter*) Because of this case, as well as the others I was seeing, I felt this issue *had* to get out of our closets, out of our small offices and to the attention of every mental health and medical professional.

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Karen: I really appreciate Margo beginning because it is Margo's work that really inspired and drew me into working with older patients. At all these eating disorder conferences, I would seek Margo out and we would find ourselves talking about our older patients in the elevator, in the lunch line, in the bathroom (*laughter*) about how challenging and yet how exhilarating and compelling the work was. I believe if you "build it, they will come." If you start talking about it, let it be known there is help available, they will find you – every week I get calls because the need is there. For this reason, I also spend a portion of time training physicians and those in family medicine residency. Years ago, when I started doing these trainings, I would teach the doctors what to look for, what to ask and how to assess and, initially ten years ago, they would look at me like I had two heads! (*laughter*) Like Margo, there is a case that comes to mind for me. Ten years ago, I worked with a sixty-year-old who had late onset of anorexia and called me as she was entering a residential treatment program. Her symptoms had never been identified as disordered eating, but while in treatment she realized there had probably been and were many unaddressed sub-acute issues her in life (which we often see.) When she came home from treatment and came to work with me, it was so inspiring to witness how much she embraced while learning about her disease. Because of her age, she had spent months undergoing every evaluative medical test imaginable and not one soul ever asked about anorexia. A phrase I often use to describe these women *when they finally come to treatment; they are ready, willing and need to upset the apple carts of their lives.* This woman inspired me and my conversations with Margo grew even more; all while I grew to further appreciate this power of connection.

Mary: When you asked the question, the first face that popped into my head was a woman who we treated in a partial hospitalization setting. This goes back about 10 years, but what was striking about her was her resilience and pursuit of health and recovery. She had developed Anorexia Nervosa in high school, had a lot of adverse life events, began to abuse alcohol, and most importantly, never forgave herself for having a special needs child due to her anorexia during pregnancy. She worked through our program ten times. Every time she came, she would do something different, something more to take care of herself. This sounds crazy, but our partial stay is 25 days, so in all she was with us 250 days. By the time she was done, she turned so much around. Just watching her was amazing. I would be very upset in discussions with her when she spoke about various providers and what they had said to her. And though I know there are two sides to everything, I knew she could not have made all of this up! Because fact is more painful than fiction and I believe her providers did not know what to do with her. A similar experience to that of Margo's patient; she was in her early sixties by the time we worked with her so had passed through the hands of many people. When she got to us the work she did was awesome. So I thought of her. The other thing that draws me to midlife besides being there myself is when we take care of adolescents and see their mothers struggling. To me that is a double threat... the intersection of menopause and puberty. Because *both* women feel vulnerable and need so much support if mom is not feeling able, has her own difficulties and needs extra support to help her daughter. And, both women are being tortured by the culture selling a bill of goods called "There's Something Wrong, There's Something Flawed About You, So Come Buy My Product." And, unless mom can help her kid become insulated from that messaging, how can she help?

Ibbits: It's pretty difficult when you are in the throes of it [an eating disorder] yourself.

Karen: We all increasingly recognize that something occurs both at the entrance to and the exit from our reproductive lives on a bio-psychosocial level that affect our bodies. So that women who are going through menopause, midlife and beyond are really rediscovering and reclaiming their identity markers.

Ibbits: There can be wonderful aspects of entering this period of life. It can be incredibly freeing. It can be a very productive time. However, Susan Kane, a wonderful clinician in New York City (she and I convened a group of treatment professionals of a "certain age" a number of months back) and I were talking and she said, "professionally and personally you can suddenly feel you're obsolete and invisible. You are a shape – you are no longer this vibrant contributing person. And with puberty... all of a sudden you don't know who you are either. At ten you know exactly who you are, but by thirteen it gets really confusing.

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Margo: It's interesting – entering puberty is, of course, so disorganizing, but you're starting to get attention for this body. You may not want it, you may not know what to do with it but that's what is happening and you have to deal with it. When you go through menopause, all of a sudden you are *not* getting attention and that's what you have to deal with. It is so disempowering for most women, especially if you've put a lot of stock in your appearance or if you haven't worked on other dimensions of yourself, and are living in this consumer culture and the age of body technology. There is nothing that tells us to embrace and accept our bodies.; even our feminine products! Everything is telling to be as sexy as we can be, and flaunting, but not having any kind of scent that might occur! You have to actually cover up your true sexuality. It is quite difficult for women. And then when their daughters, their daughters' friends and their sons' friends are becoming attractive as they go through adolescence, at the same time they feel they are losing their attractiveness. There is a lot of clash that happens; we have certainly seen where mothers feel competitive with their daughters Yes. (*agreement from the other women*)

Margo: We have talked a lot about how the women who enter treatment *do* realize they can be a negative influence on their daughters. That is why they are coming in. The woman I referenced earlier came to me when her daughter turned twelve. It was when she was twelve that her parents first took her to Weight Watchers. Not only did she need to deal with her own mind and body, but she needed to bring her daughter through adolescence without supporting the development of an eating disorder for her.

Karen: Often, the women who are coming to receive care at this time of life might actually be dealing with their daughters' emerging eating disorder. Thinking, I have lived in the torment of this for decades and am now watching it emerge in my daughter as she comes into puberty. More than a few of these women say to themselves, "if not now, when?" It becomes an added motivator. But, at the same time, and I know this is one of the things we have touched on and talked about that I have been working on with groups of women at midlife and older, there are increasing numbers of women like this in residential care. These women really need the opportunity to find their voice, to come out of the closet while experiencing so much shame about having a "teenager's" disorder. In treatment, however, these women easily fall into the same role of caregiver and repeat what they have been doing throughout their lives. Being able to connect and form relationships with other women who have that similar life experience is incredibly empowering and offers that opportunity for change.

Margo: We've talked a lot about how this work is so enlivening. As a therapist, I use myself more with my adult women than with any other patient. They so desperately need to be with a woman of substance, a woman who can identify the pressures we all feel as women from all different arenas – from the diet industry, the fashion industry, from of the forces that make us think we need to be perfect, that we can't possibly be ourselves. Just being with us and talking about those things helps them develop a consciousness and an ability to reflect on their experience. One woman I mention in "The Body Myth," I had worked with for a while. She had been bulimic for twenty-five years, was in her mid-forties when she came to me, and did *not* believe she was able to get better. And she did! She had a pivotal moment. She was getting ready for a holiday party, putting pantyhose on, participating in negative self talk, and all of sudden... it switched. She said, "Margo is right, I am a goddess." Now I had never said those words, but through the work we did and the mode of treatment the three of us use, relational cultural theory, we are so present, affirming and strength-oriented in terms of helping each woman see who she are that this is what she heard. I think she *is* a goddess. We are *all* goddesses. After twenty-five years of struggle, she had that moment.

Ibbits: We see this in our own families. I have a family member who was always curvy and perpetually trying to lose weight, and in her sixties went to Weight Watchers; it felt good, it worked well, she was getting a lot of positive attention. Then the switch flipped and she became obsessive, lost a great deal of weight and thought I was nuts when I confronted her.

Karen: It's so emblematic – it's so embedded in our beliefs. As adult women in our culture, we have been thinking and talking the language of fat forever. The woman in her sixties doesn't think eating disorder. And if she went to the doctor she would get lots of praise, again, not thinking eating disorder.

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Ibbits: My mother in her early nineties began to be wildly restrictive and no one would listen to me that she was anorexic. As you said in the article, it does not discriminate by age or stage of life.

Karen: I am working with an eighty-five year old right now who is severely anorexic.

Mary: I was going to say, it is all part of the context. As a nurse, we see many of these women. Older women can already be invisible, so the possibility of someone picking up on the illness becomes less and less. It is seen as a medical issue because OB/GYNs or other providers don't have the education or information. If these patients happen to end up in an assisted living home or nursing home, it doesn't get picked up at all. It is simply assumed this person "isn't eating" because of some other medical complication. The other thing this makes me think about is that professionals need to take a developmental perspective. What starts out as the precursor for an eating disorder is not necessarily what maintains the eating disorder. If providers could get this in their heads they might understand why women can either start to have trouble in mid-life or that they may be flying under the radar but getting into trouble because of the different role changes and bodily changes. If people thought that way, they might not miss the diagnosis.

Margo: There is a very small number of women that develop an eating disorder for the first time as an adult. It does exist, but it is the least common progression of the disease. A lot of the women we see are those who were ill when they were younger, got "better enough" but not all better. We see a morphing of symptoms in someone's history; they might have been anorexic and then it might morph into more of the bulimic symptomatology and then might move into intense exercising and some restriction. However, when they complete magazine surveys they don't "see" themselves there, and therefore don't have an eating disorder!

Ibbits: To paraphrase what you wrote in your article, they think, "but I am *so* much better. I am not doing *that*." All the while, ignoring that they may also be abusing laxatives, substances or alcohol.

Mary: When you already have low self-esteem and feel you are not deserving, it is going to take a real high alert to get you to do what you need to do to take care of yourself.

Karen: And the social isolation.

Mary: Yes!

Margo: And the pressure to keep doing this because you keep getting such positive feedback. "You look good, you've lost weight!" "Boy, she's running every day, look at her. She has so much self-discipline and self-control." It all looks good to the outside world and that is all they hear.

Ibbits: It means, "you must be a successful person and admired if you are doing these things. You must be a better person." (*all nod*)

Ibbits: It is wonderful that the women who have the opportunity to come to each of you experience both your own expertise and knowledge along with the insight you have. When women come into a residential level of care like Oliver-Pyatt Centers, we want to make very sure we avoid letting them slip into the caregiver role you all describe and make certain we are meeting their particular needs, their grief and loss issues about a life that was not anticipated, their relationships being in disarray, along with all the things that come with landing in treatment. We need to respect their life experiences and the challenges they face. My question is, what do we need to be doing, as facilities, on an inpatient, residential and outpatient basis for mature women? I know the things we have done to create groups and experiences. It can be harder for older women coming into younger milieus for all of the reasons we have discussed.

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Mary: I'm thinking of our partial hospital program, specifically because we have this challenge of having kids and adults in the program. There are structural solutions, of course, and then the need for therapist training. So structurally, I agree with what you said about separating the adults from the younger women a couple of times a week so they can do what they need to do and have the focus on their specific issues. But in the groups that are joined, I always teach the therapists to look at the tendency of the moms to take care of the younger people in the group. The blended age groups can work to your advantage because there are times when there is something interactional that takes place. It can *beboove* the adolescent to hear from someone older and visa versa! It can work to your advantage, but if it gets to be a trend it is the therapist's responsibility to point it out to the group in a kind way. "Is everyone realizing that Jenny is really good at taking care of everyone? She's a good mom and I am wondering if Jenny feels she needs to do that with us?" Usually she will say "yes." And then I say to the group, "okay, how are we going to help Jenny also get her needs met?" Someone has to name it so it doesn't continue.

Margo: Some *don't* have children and have a tendency to take care of everyone else anyway. I think we do have to put that on the table. I think paying attention to the developmental stressors taking place in these women's lives and labeling it for them must take place. They do not have the language for any of their inner experiences. They can't put it together so we have to do that for them.

Ibbits: As you reference in the article, there is also a shame that they are leaving home, spouse, children and career and the drumbeat to leave treatment prematurely is common, feeling everything is going to fall apart without me there.

Karen: And remember that these women have broader identities than younger women. They may have competencies in real life and in many other arenas of their lives.

Mary: I love the way you put that. There are very real pulls for the patient.

Karen: They have more in their lives beyond their eating disorder. The eating disorder is their shame. Their eating disorder is the place they retreat to. The other thing I have been acutely aware of as I am currently working with a woman whose daughter is going to college. My client had to go to treatment because she was medically, seriously compromised. She went two times to the tune of seventy thousand dollars in terms of what she needed to pay out of pocket: she had no health insurance. She is now trying to help her daughter write appeal letters to colleges for financial aid because she can't afford to pay for it. She had to go to treatment to *save her life to raise her daughters* but now they are in this terrible dilemma. She is trying to figure out how to talk about her adult eating disorder as a significant medical complication. She didn't have cancer or something that would be more recognized. So now we are seeing these other very significant ripples of the eating disorder. If a woman is feeling torn about the spending in the moment, she might feel it is robbing her and her partner's retirement or her child's ability to go to college.

Margo: These other arenas and competencies are the areas of their lives that feed them; they know if they go to treatment they literally won't get fed that way.

Ibbits: Taking this time to go into treatment can feel like jumping off a cliff financially and emotionally. As it is for many patients, but for these women at this point in life it can feel like a particular risk.

Mary: (*nodding*) In the paper we talked about how you are in the sandwich generation. Not only do you feel shame and guilt about leaving your children (if you have them) or a partner or even leaving your elderly parents.

Margo: Or an elderly neighbor....

Mary: Right!

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Ibbits: And no one can inflict guilt on a mature woman...like her *mother!* (*laughter*) May I just say.

Margo: Did you read that somewhere?

Mary: You lived it! Seriously, it does re-traumatize. You have to work that much harder to get someone to go to residential care. A patient we just sent – it took a lot of us – the whole group helped her work through the pros and cons. Of course, they all wanted her to go because they saw she needed it. There were only two adult women in the group at the time and the other woman was much younger. She kept saying that she couldn't do it, she couldn't do it. I finally took her aside and told her, "ultimately, this is your decision. If you are feeling a little beat up, it's because we love you and I'm hoping that is what you're hearing." She said, "okay I'll go." It took *so* much in her to get to that point. And she said, "I'm only going to go for x amount of days and I'm only, etc etc etc!" It took so much of herself to go. With an adolescent, if you have parents on board, they will go. With an adult, you have to work so hard, especially if they feel undeserving.

Margo: The forces are against women who are on their own.

Mary: Totally.

Margo: Often their partner or parents don't understand. Or the partner might not have known.

Mary: And they're catching up.

Margo: Their parents don't know. Their kids maybe know and don't know at the same time. One of the things I hope we can convey is that we have all had cases of mature women who come to us whether they are in their forties, fifties, sixties or older who really believe they cannot get better; who believe they are sentenced to this for life, are so deeply ashamed they can't get better. *But we see them get better.* It's not just seeing them get better, it's nurturing it and helping them find themselves for the first time. As you mentioned, they have all these abilities and all these splintered parts of themselves. They are so high functioning that no one has a clue anything could be wrong. The contrast between the inside and outside is so extreme. They come to therapy with someone like us; they are affirmed and allowed to be imperfect, allowed to begin to feel for the first time. Gradually, they are able to develop real coping mechanisms so they don't need their symptoms. It can take a long time but it really is possible.

Karen: The experience of self-empathy is so often foreign. That's the other thing I work with, teach, model and embody with the women I work with – helping them see it is a radical act to learn and develop self-empathy and a life-saving one. To begin to participate in mutually empathic ways in their relationships rather than one way empathy which has been the nature of their lives chronically. And I use that last work specifically because the large majority of adult women have been struggling for years and for many they perceive the disease as a chronic, but very hidden and often unnamed experience. So the experience of being in a relationship with a therapist, of being encouraged, of being offered hope but learning empathy, receiving empathy and how to practice it for themselves plants the seeds of change. As Margo said before, we see these women getting better.

Margo: One of the core principles of Relational Cultural Therapy (RCT) is all about mutuality and empathy. There's a concept of fluid expertise; that both the patient and therapist have expertise and we share this expertise. It's such an even playing field so it really does help a woman to understand she not going to come into therapy and feel inadequate. She's going to come in and we are going to affirm all her adequacies. We are going to help them understand they can have these adequacies and *still* have these problems. They are going to partner with us because we need all of what they know about themselves; we are not the experts about them. Among the first things I say is...

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Mary: I'm a goddess and so are you...

Margo: (*laughter*) Exactly.

Ibbits: That's the crux of it, that's all you need to know. Boom. You're a goddess. We're done.

Margo: I say, "I'm the expert about eating disorders but you are the expert on you. I often give them the term "fluid expertise." Many have been in some sort of treatment in the past. Many not for their eating disorder. I want to know from them what has worked for them in the past and what hasn't worked and affirm all those strengths. They don't have to leave them at the door.

Mary: I also wanted to add that when we are talking about all of the things we do in therapy, the other challenge is that you have to help the patient to somehow extend the feeling she is experiencing in the session. It's not just about the therapist and the patient; you really need to help the patient identify people in her life that will engage in that way and/or teach them how to engage in this mutual way. I'm thinking of another woman who got sick when she was seventeen, with two mentally ill parents at home. She was terrified of leaving the home and she finally came back to treatment at forty-seven and is now driving a car (got her license,) has a volunteer job, is leaving her home, and may leave her parents to go into supported housing. I am crediting our care manager because I have people at the partial level who will leave the building and help the patients with those every day practical things. This is why developmentally you have to understand these patients. You might look at this particular patient and think what's the big deal about going down to the DMV? For her and others it is terrifying. You might as well be twelve in the body of a forty-seven year old. She didn't get to practice any of these skills. We have to identify, train and put in place care managers, life coaches or peer mentors. If it can't be the family of origin, then you help the patient create the family of "choice." The therapy session is a little dot, a little island in the patient's life. If you don't realize this or address it by helping her grow in her relationships and connections with others then you are doing her a disservice.

Margo: These are all concepts in RCT, the fluid expertise. You really *are* an expert about you. You are already very, very competent; I am just going to help you.

Karen: I am putting a plug in again for the kinds of groups I have been doing with mid-life women! In terms of residential, again, I think if you build it they will come as well as in outpatient, partial, etc. As you have more women seeking care they become an incredible resource to each other. As we have said, they are often incredibly talented and gifted individuals creative in their own unique ways. Like Mary's case, many of the women in my group are very creative in specific tasks: sewing, needlework, art; all different avenues of very singular, isolated activities. I liken the group from sewing in isolation to creating a quilting circle. This what I see, when these women find different ways of being in the world where these connections can grow it further empowers them.

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