The Medical Mind
Personal Perspectives on Bipolar Disorder – Part 1

Voiceover (00:04):

This is The Medical Mind, a podcast about innovations in mental health care from The American Psychiatric Association. This special episode is co-presented by SMI Adviser, a clinical support system for serious mental illness and by NAMI, The National Alliance on Mental Illness. SMI Adviser is funded by The Substance Abuse and Mental Health Services Administration and administered by The American Psychiatric Association. These podcasts include the real life experiences of people with mental illness and family members. Some of the content includes discussions of topics such as suicide attempts and may be triggering. If you are in need of support at any time during the podcast, please contact the NAMI helpline at 800-950-6264, available from 10:00 AM to 6:00 PM Eastern time, Monday through Friday. To receive 24/7 crisis support, please text N-A-M-I to 741-741, or call the National Suicide Prevention Lifeline at 800-273-8255.

The topic for this episode is bipolar disorder. It is the first of a two-part discussion led by Dr. Ken Duckworth. He leads a deep discussion that offers insights for individuals, family members, and mental health professionals, living with it, loving someone who has it, treating it, the impact of cultural identity, and so much more. Let's dive right in.

Ken Duckworth (01:20):

Hi, this is Dr. Ken Duckworth. I'm the chief medical officer for The National Alliance on Mental Illness, also known as NAMI. Today's conversation is about learning from the experience of living with or loving someone who has bipolar disorder. We have three fabulous guests today, Marleyna Illig, who lives with bipolar disorder, Monique Owens, who loves a daughter with bipolar disorder, and Dr. Melvin McInnis, a professor of psychiatry at the University of Michigan, who studies people who live with bipolar disorder. This conversation is designed to make a difference for people who have been given a diagnosis of bipolar disorder, and to extend their learnings, so that a listener can pick you some developments for their own life. So let's start by just saying hello and checking in on how everybody's doing now. So would you just introduce yourselves? Say how you're doing today, just for starters.

Marleyna Illig (02:24):

Hi, I'm Marleyna, and I am doing very well today.

Ken Duckworth (02:29):

Monique.

Monique Owens (02:31):

Hi, I am Monique Owens, and I am doing fantastic today. Thank you for asking.

Ken Duckworth (02:39):

And Dr. Melvin McInnis.

Melvin McInnis (02:42):

Good afternoon. I'm doing very well. We are enjoying a very nice day here in Michigan. The sun is shining, and so good things happening today.

Ken Duckworth (02:50):

Excellent. So this is a conversation about bipolar disorder and what you all have learned. Marleyna, I'd like to start with you. As you reflect upon your experience, is there anything you'd like to share about what you've learned?

Marleyna Illig (03:07):

The biggest thing I've learned is that there is no way I am ever going to have learned everything. I've become so much more aware that my mind does not work the same as everyone else's. And it's just basically been acceptance of my mental challenges, and learning how to not be so hard on myself, but not using it as an excuse to not live my life.

Ken Duckworth (03:39):

There's an acceptance, a moving ahead. There's a lot of pieces to it. Do you want to develop a little bit more the idea of what you've accepted, that your mind might be a little atypical in some ways?

Marleyna Illig (03:53):

I really feel like the past year in itself, since I started extra therapy and really taking care of my self-care and mental health, I've learned that just because my mind doesn't work the same way as others does not mean that there's anything wrong with me. I feel like a lot of the time, I used my situation with bipolar and the self medication that came with it as kind of an excuse to not do my best and not really get my life together. I think a lot of the acceptance for me is realizing that I am not crazy. And I think that's a big thing, is realizing there's not anything wrong with you, it's just that your mind works differently, and that I can still lead a really good life, just you have to work a little harder.

Ken Duckworth (04:46):

So you have a very sophisticated take on it, which involves both acceptance, but not self blame, while still moving ahead. May I ask how old you are?

Marleyna Illig (04:55):

Yes, I will actually be 31 in about three weeks.

Ken Duckworth (04:59):

What age were you when you started to put these pieces together, okay, I have this phenomena, I'm not crazy, I have to deal with it, and accept it, but also move on?

Marleyna Illig (05:11):

That was a year ago. It was age 30. I was diagnosed at age 14, and it's been an ongoing struggle ever since. And it wasn't until just about this time last year that I realized you're not crazy, and you're going to need to take care of yourself. There's going to be work involved, but it's worth it.

Ken Duckworth (05:32):

Were you given the diagnosis of bipolar disorder at age 14?

Marleyna Illig (05:36):

I was diagnosed at age 14. I've been diagnosed with other things since, but my first diagnosis was at age 14.

Ken Duckworth (05:44):

Of bipolar disorder, so you think they got it right the first time.

Marleyna Illig (05:48):

I think they've gotten it right every time.

Ken Duckworth (05:51):

Got it. And the journey has been more within you, but it's a lot to take in as you're growing up and developing an identity.

Marleyna Illig (06:00):

Yes, it absolutely is. And I self medicated a lot to not have to deal.

Ken Duckworth (06:07):

That's a very common response. And I wanted to ask if you feel comfortable developing that a little bit. How did you experience the self medication idea?

Marleyna Illig (06:15):

I actually started binge drinking around age 17, and eventually, I became addicted to opiates for five and a half years. I actually just celebrated seven years clean from drugs on the 23rd of July.

Ken Duckworth (06:34):

Congratulations.

Marleyna Illig (06:36):

Thank you.

Ken Duckworth (06:37):

It required a full stop. Right? So you have no contact with substances.

Marleyna Illig (06:42):

No. I quit drinking. I quit smoking cigarettes. The only thing I take is very occasionally, my anxiety medication. But other than that, I don't do any self medication.

Ken Duckworth (06:52):

Boy, that's quite an achievement.

Marleyna Illig (06:55):

I think that quitting drugs really forced me to sit with myself because I didn't have what was taking me away from my mind, so learning how to sit with myself and sit with my emotions, and learn how to deal with them on my own was a really big stepping stone in accepting my disorder, and also learning how to handle it.

Ken Duckworth (07:20):

Did you get support from family or professionals to help you with either the idea of stopping the use of substances, or in this kind of advanced acceptance? Do you think it was clinicians, family members, church? What were the forces that helped you? What were the supports you had?

Marleyna Illig (07:41):

It was my mom, it was my mom.

Ken Duckworth (07:42):

Your mom.

Marleyna Illig (07:43):

My grandparents. And I did have support from my behavioral health provider. But as supportive as they were with just getting me to the places I needed to be, it was my family that kept me there and kept me doing what I needed to do to stay on the right course.

Ken Duckworth (08:04):

So were you able to discuss all this with your family? Many families still struggle with shame and prejudice.

Marleyna Illig (08:11):

Oh, I'm so open with my family. I'm really fortunate. But even the last year, as I've gotten more familiar with my mental health disorders, my mom has been learning completely different ways on how to work with me, and learning a lot herself about my mental disorders, as I've learned about it. So we've been creating a really good dialogue as to how to work together with it.

Ken Duckworth (08:39):

That's a beautiful story. Was NAMI helpful to you or your family?

Marleyna Illig (08:45):

Honestly, I feel like NAMI did a big part in saving my life. I was going through a really difficult time around this point last year, and I decided to volunteer with them, and them continuing to talk to me really helped me by giving me responsibility because going out and sharing my story and talking to the kids in the community, and the adults, I think ended up being really therapeutic for me, and kind of giving me that purpose. Made me feel like there was still things worth fighting for and worth living for.

Ken Duckworth (09:19):

That's a beautiful statement, and I think that's pretty well backed up by the research literature that giving to others, having a sense of purpose, developing meaning from your experience makes a difference. I want to thank you, Marleyna. I want to ask Monique Owens. As a mother, I'm interested ... You're not Marleyna's mother, I want to make that clear. But Monique, my understanding is that you're a parent of a child with bipolar disorder. And I was interested in your process of understanding this.

Monique Owens (09:51):

Yes, I am a parent of a person with bipolar disorder. She will be 29 on Sunday, and we have been dealing with this behavior since she was about 13, but did not get an official diagnosis until she was 21. By that time, she had gotten herself in trouble with the law, and I was already into NAMI because of my other children. From learning from NAMI, I was able to help her, pull her through that process. As of January of this year, was the first time Brandy talked about publicly, her battle with bipolar, and how she processed through that. And it was difficult as a parent to watch her go through all of that, and feeling helpless that I couldn't change things for her. But I never left her side.

There were times with her behavior, we as a family just wanted to just let it go. But somewhere along the way, when she realized that I wasn't going to give up on her, and even through that process, we were still there to help her through, to talk with her, to show her that she needs to get the help. And she actually when to get help and do that process, even when she was going through the court system. It still helped her become calm. She came to grips with her illness. And while she was in jail, she was talking to the other young ladies in there and helping them through their process too. Right now, her best thing is to come and talk with us. She used to self medicate. What she did was marijuana. That was her vehicle of choice.

But her main grip was stealing, and it's theft that got her in jail. So she had learned when she had that moment to sit with herself in jail was when she came to herself and said, "I need to really get help and get out of this." And so now the family is rallying around her. Her siblings rally around her. We all check in on her on a consistent basis. Her boyfriend comes to me and says, "I'm not sure what's going on with her today. What do I do?" So we have everybody, even her employers. They help her when she's having a bad moment. So we're helping to keep her on track.

Ken Duckworth (12:24):

So I hear a lot of love and a lot of communication. Did you know anything about bipolar disorder before this came into your family's life?

Monique Owens (12:35):

Not at all. This was completely a blindside to us. I was aware that something was happening, but I did not know what it was called. Far from my mind was it bipolar. I knew that she had been diagnosed with ADHD, but it started changing, and I said, "That's not ADHD. What is this right here?" And so it was not until I got into NAMI and I started teaching the family to family course, and the basics course, where I started learning a lot more. And through those resources, I was able to give her the help that she needed.

Ken Duckworth (13:12):

Excellent. So NAMI's family to family and NAMI basics courses both are psycho education programs to help people learn more about the conditions that happen very commonly, and also an emphasis on self-care and sustaining yourself to be a loving family member. Did you take away anything else from those courses?

Monique Owens (13:35):

I took away self-care was the number one thing because I was going through physically stress. The stress was landing me in the hospital way too many times. She would disappear for days at a time, and then not knowing where she was. And I was always in a worry, anxiety state myself, so much so that I wound up having to go see a psychiatrist so I could get some help. And then I was on medication just trying to stabilize myself. So NAMI helped me understand that it's okay if you have to get that help.

Ken Duckworth (14:09):

That's correct.

Monique Owens (14:09):

Because I have to be able to help myself before I can help her. That was a turning point for me, that I learned to take care of me. And when I did that, I was in a much calmer state to be able to help her. And then the rest of the family started seeing the change in me, and then they started coming on board like, "Wow. Mom's not fussing as much. Or mom is not stressed out as much. Or this would've taken mom out before, but she seems to be a lot calmer. What are you doing?" And I said, "Hey, I'm learning." And believe that the education is key because once you know what's going on, you become more empowered in how to handle it, and therefore, the fear is gone. And now we can work with the solution.

Ken Duckworth (14:57):

Was it difficult for your family to take up this topic? Because not every family finds this easy because there can still be a lot of shame and prejudice in our society.

Monique Owens (15:10):

It was not as difficult as we thought because when I got into NAMI, my first night, I realized that there were other families going through the same thing, which gave me a relief, which gave us a relief that we're not crazy. We are not alone. When we realized we were not alone, and I talk with the family and say, "Okay, this is what's happening with her. What can we do to help her?" And in turn, my whole family has actually taken the basics course. And some of them have taken the family to family course, so getting the education throughout the family helped us be able to help other families.

Ken Duckworth (15:51):

I wanted to ask you, Monique, about her experience of going to jail. The overuse of the correctional system for people with psychiatric illnesses is a huge problem in America. But it sounds like for you, it was a moment when your family was able to pull together. Is that accurate? Or just say the consequence of jail had meaning for your daughter, or how do you think about it?

Monique Owens (16:20):

For my daughter and her situation, I think that the jail consequence is what was needed for her. She did not want to go to the doctor. She didn't have the hospital experience that other people went through. Hers was more on the track of the justice system.

Ken Duckworth (16:40):

I see.

Monique Owens (16:40):

It was as if she was making a beeline for that, so I had to learn how that worked. And learning how that worked helped process through the situation where, yes, I believe that a lot of people are in that system unnecessarily.

Ken Duckworth (16:58):

Yes.

Monique Owens (16:59):

That they could go through the medical and get the treatment and so forth.

Ken Duckworth (17:03):

That's right.

Monique Owens (17:04):

And I strongly suggest that people go through the medical process. Do not go through the juvenile justice or the justice system period because there's too many of them there. They need to be actually treated alternatively.

Ken Duckworth (17:18):

Wow. Monique and Marleyna, I want to thank you both. Dr. Melvin McInnis, professor of psychiatry at The University of Michigan, Dr. McInnis, you study people who live with bipolar disorder. And one of the things you've been trying to sort is: What helps people do well with this common and very serious condition? And I was interested in your thoughts about that as it relates to our two experience experts who've already spoken.

Melvin McInnis (17:49):

Well, thank you very much, Dr. Duckworth. And thank you to Marleyna and Monique for being so descriptive and eloquent in describing your experiences. One of the two things that you both highlighted the importance of, and that was information and education. And also, what I was impressed with your comments, Monique, about how really easy it was to go and get information. And I was also just impressed with Marleyna's point about the realization of the needs to get the substance abuse under wraps and to get that treated. That really emphasizes the importance of NAMI, both in the context of into and education. And in studying what helps people to get well, what keeps them on the road to wellness, is precisely information and education.

What we're learning in our studies is that the individuals who are able to utilize the information from ever so many different sources, from their abilities to engage their family members in their care, and their ability to work with their therapists and treatment providers is really key. What we've also learned is that we are students ourselves, the treating community. We're learning from individuals with the illness. We're learning about what it is that keeps them well, and what it is that causes them to have problems. The personalized elements of care are really highlighted here because one of the important things that a care provider can do is really learn what the triggers are for an individual, and what the triggers are in the context of their difficult issues. It could be relationships. It could be jobs. It could be any number of things. And also to learn what their strengths are, we want to be able to identify ways to maximize the strengths and ways to minimize the weaknesses.

Ken Duckworth (19:48):

That's excellent. You mentioned the concept of triggers. And I've been very interested in this in the self knowledge perspective. I wanted to ask you, Marleyna, first, if you've come to identify things that are predictable triggers for you, that are likely to worsen your condition. And on the flip side, what are the pieces that you've identified that are strengths that you can activate to reduce the risk of a recurrence of an episode?

Marleyna Illig (20:21):

I don't get triggered by much, but when I do get triggered, it's really, really heavy. And I find that what has triggered me the most is my relationship with my mom. We have a great relationship, but when we have fights, and it can be something really small, but any situation where I'm feeling like I'm not doing something well enough, it is enough to throw me into this big tailspin. The thing that's interesting is it's not every time. I never know. There's really no way to know what to expect. But a lot of the feelings that get triggered for me is feeling like I'm not enough, or that I'm not good enough, that I'm defective, that no matter what I do, it's just not sufficient. And I think that's always been a big trigger for me, feeling like I'm just not good enough.

Ken Duckworth (21:17):

Well, it sounds like you've gotten pretty far on that journey. But interpersonal stress is definitely one well known potential risk factor for a recurrent episode. Would you agree with that, Dr. McInnis? Interpersonal conflict or distress, do you want to talk a little bit about the research angle on that?

Melvin McInnis (21:38):

One of the underlying features of bipolar disorder is an element of reactivity. And reactivity can be in the moment. It's an emotional response, and there's a level of activation, the amount of energy that can erupt in an individual, and the valence, or the emotional positivity and negativity that the individual has. Individuals with bipolar disorder appear to have just a little bit more reactivity of an unstable mood. That's really the inherent element of bipolar disorder is this nature of going up and down. So what we are interested in learning more about is how we can look at the noise in the system, if you will, an individual's level of emotional reactivity, just as measured by measures that would reflect how someone's going up and down, for example, in the sound of their speech over the course of their week, or their level of activity.

So the individual would be able to learn how they're doing and what their level of instability or their reactivity is for that week. One would know when one was at a period, or in a period of time when one was particularly vulnerable to react in a way that would be less than productive. As Marleyna's saying, it's difficult to predict when these things will go off. And so it would be wonderful to know when one was at a particular risk period for this to happen, and could take on a difficult conversation, for example. Or if one was at a period of time where things are just not going so well, and it's probably best not to go into particular topic, when one is in a particular state. So it would be very helpful to be able to identify risk phases of instability.

Marleyna Illig (23:27):

I can say that my big risk is when I have a lot of stressors going on, I have a lot of events going on that are outside of my control. Or for example, I just started a new job at a rehab, and I love it. And it's a good stressor, but it's a lot of stressor because I'm out and I'm not getting the sleep I was before. And I'm also working long hours. And even though I absolutely enjoy it and I love it so much, it's a big change in life. And it's a lot going on, and I'm learning a lot. So even though things are going really well, those stressors are in the back of my mind. And so that's a situation where something that usually would not upset me in a conversation with my mom, upset me recently because I do have all these other stressors going on.

Ken Duckworth (24:18):

Right. There's a whole literature on stress management and sleep. And I wanted to talk a little bit about sleep because many people have told me in my clinical practice that if they can maintain a regular sleep schedule, many people find that very protective. I wanted to ask if that's been your experience, Marleyna.

Marleyna Illig (24:40):

Yes. I've always had issues sleeping. But luckily, I've been a lot better about it. But yeah, when I don't get enough sleep, that can make things really turbulent. We had a house fire last year, and there was a lot of stressors going on. And I was staying awake for upwards of 20 to 30 hours at a time, and that was when I really realized, oh, my goodness, now is when you need to go, and you need to get therapy. And that's what's really helped me over the course of the year. But it was my poor sleeping habits that were really sending me into a negative mindset, which is, well, it was the catalyst in me finally get the therapy.

Ken Duckworth (25:20):

Well, this is again speaking to your capacity for self learning because identifying the onset of a recurrence of a bipolar episode, whether it's mania or depression, turns out to be really important. Monique, I wanted to ask if your conversations in your family have looked at stress and sleep as you've worked together to support your daughter.

Monique Owens (25:44):

Absolutely. That has been the focus of a lot of our talks, is as they were growing up, I noticed that they were more like insomniac. And I had to fight so hard to make sure that they would go to sleep. They've very outgoing when they were children. They're adults now, so they're still outgoing. They always are the life of the party. So I had to make decisions where, no, the company cannot come because this is a day of rest for us. The whole family has to shut down because we were all suffering when someone was not sleeping adequately. And my children's ages fluctuated. The older ones had to be quiet so that the younger ones could sleep. And the older ones wanted to keep the lights on all night and keep the games going all night, and things like that. So I had to make a decision that, no, we have to shut this down. Everybody has to get rest because when we didn't get the rest, that's when I noticed we fought more with each other.

Ken Duckworth (26:52):

More conflict, more stress.

Monique Owens (26:53):

Yes.

Ken Duckworth (26:53):

But also, did that lead to any of the mood episodes?

Monique Owens (26:59):

I think it did because there was always something going on. I don't think there was ever a dull moment in our life for the last almost 40 years. I just don't think there was ever a quiet moment. But I noticed that when the stressors would come, the mood would change very quickly. And then it would become aggressive, where she would slam things down, or slam doors.

Ken Duckworth (27:22):

Irritability, hostility, that the highs aren't always feeling up, excited. They can also be irritable, hostile.

Monique Owens (27:32):

Yes, hers were very irritable, hostile, most of the time. Then there were times when she would be so loving and caring, and everyone was like, "Oh, this is great." And we would capitalize on that feeling, where the family would all rally together. We would all go out. We would do things to keep it going. But then there were times when we could see we're in the depression side. We're in the side where we have to be more caring to her, giving her more love and assurance that she's fine, she's more than enough. She is great. She's doing well. And so the ebbs and flows that she was having, the family was feeling the same thing.

Ken Duckworth (28:12):

The family was almost required to use different strategies for the different phases of the mood condition. Would you agree?

Monique Owens (28:21):

I agree. And there were times, because we weren't educated on it, we did not do well with it.

Ken Duckworth (28:28):

Well, it's important to be very gentle with yourself because very few people have advanced knowledge of this before they find NAMI, or a good practitioner, or have a thoughtful general practitioner, family care doctor, or minister. You need somebody in your life to help you learn. Dr. McInnis, can you comment on sleep regulation and stress management as it relates to bipolar disorder?

Dr. Melvin McInnis (28:55):

Sleep is really just fundamental to humanity, and sleep is incredibly important as a marker in bipolar disorder. Very frequently, we see individuals that have bipolar disorder that have even just one or two nights of really disrupted sleep, and that is the beginning of a manic episode. It's incredibly important to keep tabs on sleep. And very often, these things can happen in a very short time period, can happen over a course of two to three days. And so the family and the individual are best advised to have a discussion with their care provider, and have a strategy at hand to be able to implement very quickly if an individual with bipolar is losing sleep. And it could be, like Monique was saying about making sure everybody, if there's rules that get in place. But frequently, it's important to have an extra dose of a medication to take, should there be indicators that the sleep is really going south. Often, it's difficult to get into see the care provider in sufficient time to adjust the medication. It's really important to have a really strong plan in hand.

And so far as stress, stress is something that occurs in our life. I think that Marleyna really exemplified that by pointing out, yes, she's in a very good position, and really exciting new job. But any new life event that's a positive event can cause a bit of stress. I mean, getting a marriage, or getting into a new school, or a new job, those are all wonderful things, but they still cause a little bit of stress. One of the things that I've talked to my patients about is that when you're headed into a stressful time, make

sure you take time. If you can possibly prioritize some personal time just to relax and recover, it's very important. And family members can really give you a good idea as to how things are going.

Ken Duckworth (30:50):

Requires a lot of love and trust though.

Melvin McInnis (30:52):

It does.

Ken Duckworth (30:53):

To be able to accept feedback from someone.

Voiceover (30:57):

That's all for this episode of The Medical Mind. Look for the second part of this discussion led by Dr. Duckworth in The Medical Mind episode list. The mission of SMI Adviser is to advance the use of a person centered approach to care that ensures people who have serious mental illness find the treatment and support they need. Learn more at smiadviser.org.

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Personal Perspectives on Bipolar Disorder – Part 2

Voiceover (00:04):

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Ken Duckworth (01:10):

I want to ask Marleyna and Monique about your cultural identity, whether that's racial, religious, sexual orientation, whatever it may be, how has that factored into your experience or has it factored in at all?

Marleyna Illig (01:26):

For me, it honestly hasn't. My mom is White and my biological father is Black and I grew up in a predominantly Black church. It wasn't even until around the past year, since I worked with NAMI and started going to church again that I realized in non-White communities, it's actually less discussed mental health aspects. I was very surprised because I never knew that. I actually started going to the church I go to because I did a presentation there with someone who was also a presenter at NAMI, but she went to that church, which is also predominantly Black, had an entire series on mental health and about how it's important to take your medication no matter what. Even if you think your medication is working and a lot of times people will want to stop it, no, you need to continue taking it. That was something I didn't realize was so unusual to speak about in that community, so while I've never had issues with it or I never realized that there is a particular stigma in that background.

Ken Duckworth (02:47):

What do you think has been your experience within the church? Do you feel like it's an area that the people want to talk about? Is there still shame about it?

Marleyna Illig (02:58):

I've never experienced anything negative with it, but my brother had actually taken his own life when I was 14.

Ken Duckworth (03:08):

Oh, I'm so sorry.

Marleyna Illig (03:08):

I was surprised because they actually held his funeral at our childhood church, so I feel like, probably, there was a lot of progression that I didn't even realize at that young age. I never felt discriminated against. I never felt any stigma from my church or any people who were close to me in the religious circle.

Ken Duckworth (03:33):

Yes.

Marleyna Illig (03:33):

I'm really fortunate for that.

Ken Duckworth (03:35):

It sounds like your challenges began about the same time you lost your brother, if I'm understanding correctly.

Marleyna Illig (03:43):

I ended up in the hospital for the first time for a suicide attempt a month after my brother took his life, so yes-

Ken Duckworth (03:43):

Oh, I'm so sorry.

Marleyna Illig (03:50):

... it was at the exact same time.

Ken Duckworth (03:52):

Incredible trauma. Could your family talk about it then, that particular issue, because many families have struggled to talk about a loss like that?

Marleyna Illig (04:02):

No, they didn't really talk about it much. My brother who found him is, actually, still in the throes of addiction. He's been an addict for 22 years now. That's a really long time. He's been using since he was 11. He uses it as a reason to continue using, so there's a lot that's not talked about in regards to my brother's passing.

Ken Duckworth (04:27):

Boy, there's a lot of pain there. Monique, what about your cultural identity? Has there been any impact of that on your experience or not so much?

Monique Owens (04:40):

Interestingly enough, it really has. We are of the African-American descent and because of that, we don't talk about that, culturally. It is the stigma in our community to not talk about it. I grew up in church. Both of my parents are ministers, so I got the whole gamut as a young person. When I started having my family and I started seeing behavioral changes that was contrary to what we're taught in church and I started seeking help because I realized that what was happening was much more than just typical teenager children's behavior. When I started asking questions or asking for help, of course, it was, "You need to pray a little bit more or you need to discipline them a lot more." I said, "If I pray anymore, Jesus himself, is going to come down here and say, 'Can you chill?'" If I do any more corporal punishment, then I'm going to wind up in trouble. So I think that I've covered all of those, but something still was not happening. It's something else.

It's not what we were taught. This is not typical, so because I've always felt it was something else, I kept trying until I found out what it could be. When one of my got diagnosed with ADD, I said, "Oh, I'll take that. Okay, great. I like that." They were looking at me like, "Why are you accepting that?" I said, "Because I have an answer." We came out of the church for years because I felt like I was not getting that help that I needed; however, I did not hold them accountable because I understood that they were shying away from something they did not understand. I got back in church about four years ago, which was when I got into NAMI and started understanding and started talking with people and understanding that I was not the only family going through it and people were coming to me and saying, "This is what's happening."

Monique Owens

I said, "Oh, well, did you check to see if this could be the problem?" When they did," they're like, Oh, thank you so much. I never thought about that. We got the help we needed. I'm learning that in our culture, all we have to do is just be brave enough to talk about it. That's what I, and my family are doing. We're brave enough to talk about it and now we're starting to see more people coming through and saying, "Hey, I understand. Let's remove the stigma. Let's figure out how to get us help so that we can keep our people from going to jail or being misdiagnosed or whatever, but let's get them into therapy. Let's get them to find out what's the best course for them." So for me, it was bad, but then it wound up being good.

Ken Duckworth (07:24):

I think you should acknowledge that the psychiatric establishment or profession has a history of misdiagnosis, over-diagnosing African-Americans. That has contributed to some of the lack of trust-

Monique Owens (07:38):

Oh, absolutely.

Ken Duckworth (07:39):

... and I just want to acknowledge that.

Monique Owens (07:40):

That is very true. That there's fear too, because that's what was told to me, "Oh, you don't want to go get that because they're going to put your child on medicine," or, "They're going to give you this stigma." I said, "Look, I'll take the label if that's going to help my child."

Ken Duckworth (07:53):

Right.

Monique Owens (07:53):

But that was my perspective.

Ken Duckworth (07:56):

So you were able to both transcend the culture within the church, which was discouraging you, but also overcome the complex history between the mental health field and African-Americans in order to get the evaluation and get the help?

Monique Owens (08:11):

I did because the pain was too great that we were feeling and we needed some answers. We needed release. I found out it was generational and so I started asking questions of the older people, "What was the behavior like when you were a child or your siblings?" I started being able to connect the dots and went, "Oh, I see what this is doing." When I started having grandchildren, I started seeing these things early, so now we are able to get them treatment to get that to them early. They don't have to go through what we went through.

Ken Duckworth (08:44):

So you're the whole next level up thinking across the generations. I think it's a true statement that if you have bipolar disorder in your family, your individual risk is for mood disorders. But I want to ask Melvin McInnis a little bit about a common question I'm asked. My family member has bipolar disorder. What does that mean for me genetically?

Melvin McInnis (09:05):

I've studied the genetics of bipolar disorder for around 30 years. I began my career working with families that had bipolar disorder amongst them and it was very clear that there were families in the U.S. and around the world that have a larger number of bipolar disorder or other mood disorder individuals amongst them. When there is bipolar disorder in a family, a sibling, a parent, or an offspring, or just any distant cousin, there is an increased risk. Now, it's not a given that anyone in the family will have bipolar disorder, nor is it 50/50. It is, in fact, approximately five to 10% likelihood that someone will develop bipolar disorder if you have a sibling with bipolar disorder. Now, what does that mean?

The problematic thing with probability is that most of us have a very dilute understanding and probability. So yes, one is at an increased risk, but it is not the 50/50 kind of risk that we think about in the context of genetics, so it's an increased risk, but it's certainly not a given. The risk increases, it seems, as we notice or observe an increased number of individuals with bipolar disorder or other mood disorders in the family. If two parents have bipolar disorder, there's a much higher risk that their offspring will have bipolar disorder.

What is likely going on is that there are a number of genes or variants of genes that predispose in some way to bipolar disorder and a collection of these risk variants accumulating and any one individual may increase the risk. Now there are other factors and Marleyna pointed out the points about the stressors and the context and so there are many factors that contribute to the risk and genetics is one of them.

Ken Duckworth (10:54):

Excellent. I wanted to ask Marleyna, what advice you would have for mental health practitioners based on everything you've learned? What would you like to say to them?

Marleyna Illig (11:07):

I think the thing that I would want to say the most to them is, "Just listen really well." I feel like a lot of people I've gone to in the past, the ones that have listened to me and really worked with me and treated me like an individual and not just another client are the ones who have made the biggest impact on my life. I feel like it's so easy to lose track of everyone and lump them into one whole category. When in reality, no one's mental disorders are the same. No one has the same recovery. No one has the same treatment meds don't even work the same for everyone. And so where it's really easy to be like, well, this is how I handled this person that worked for them. That's not how it's going to be with everyone. I feel like it's really listening and working and making it more tailored to the individual is what I would recommend the most. We're not all the same.

Ken Duckworth (12:07):

That's a great perspective. Monique, what would you say to the mental health practitioners listening to this conversation based on what you've learned?

Monique Owens (12:16):

I would say that the family involvement in the treatment is of utmost importance. You have to involve the family. My experience was when the therapist or the psychiatrist wanted to talk to my person without my presence, and I can understand the patient confidentiality. I get that. My challenge was when you're asking them, how are they feeling, you're not getting the entire story. You're getting a skewed view based on their view of things and if you're talking about an individual who does not accept their mental challenge, you're not going to get the whole story. So ask or involve the family members that you're sending that person home to. The family needs to be trained. The family needs to be understanding what is happening with their individual family member and get everybody involved in the treatment. That's what I focused on. There were times when, even though I know the therapist could not say anything to me, I've let them know upfront. This is what's going on.

Ken Duckworth (13:29):

Monique. This is a crucial idea that you've conveyed. You can give information even if they're not in a position to share information because the individual has forbidden it, but you're still allowed to give information.

Monique Owens (13:46):

You're still allowed to give information and when I learned that, I teach that in my courses, even if you don't think they're listening, give it to them anyway. I've also taught my family members to advocate for themselves. Don't just take word, study your own illness. Speak up when you're feeling the things, because I'm not there to do this. This is a life that you have to live and you need to be able to speak to for yourself. I think that involving the entire family helps with the healing process. I'm not going to say it's going to be quicker, but at least everybody is on the same page.

Ken Duckworth (14:23):

Hmm. Melvin McInnis, do you have any research findings on being listened to, as Marleyna said, or involving the family, because I think those are bedrock principles of good recovery prognosis? Is there a research literature to support to back up their experience?

Melvin McInnis (14:44):

Well, there's a research literature that emphasizes empathy and the ability to listen to individuals and to understand the story that's clearly very, very important. I think that the emphasis really needs to be on the fact that management of bipolar disorder, like any human illness is really a collaboration between the individual who bears the burden of the disorder as well as the family and the care providing team. I think that that is a really critical elements to that. I also just want to really emphasize what Monique said about the importance of the family member conveying their information to the treatment provider. That information is incredibly helpful and people need to know that they can provide information.

The therapist and the treating individual can read it and can listen to it, but the law prevents them from revealing information about the patient themselves. Research indicates the more information that the individual treating provider has, the better that they're able to prevent the recurrence of illness. Was one particular study that looked at the results of several studies in and of itself, a meta analysis, showing that the greater the intensity of the information that the care provider has, the better they're able to design the treatment program and prevent hospitalizations.

Ken Duckworth (16:09):

Their experience is really backed up by the scientific literature it sounds like.

Melvin McInnis (16:13):

Absolutely. Absolutely.

Ken Duckworth (16:14):

Well, I want to shift gears and ask you what you would advise somebody who was recently given the diagnosis of bipolar disorder and might have complex or ambivalent feelings about that. Based on what you've learned, Marleyna, what might you offer to them from your vantage point?

Marleyna Illig (16:34):

Well, the big things I would say to them is, "One, you're not crazy; two, it's not going to be an easy fix, but it's worth it." There's going to be things that will work. There's going to be things that won't work. There's going to be things that will work and will stop working and the thing is it's ever-changing. A lot of people will think," Oh, well, this medication didn't work and that one didn't work. I give up trying." I know a lot of people like that and the thing is, it's not an easy fix. I've been on medication since I was 14. It's taken me a good, I don't know, 15, 16 years to get on the right combination that has helped me along with therapy. I would say there's nothing wrong with meds, but what may work for one person is not going to work for the other. So all I can really say to them is, "You're not crazy. It's not going to be easy, but it's worth it to get the help."

Ken Duckworth (17:32):

That's a great message, Marleyna. Monique, for a family that has come to learn that their child or teenager or young adult, these are typically the times when the diagnosis is made, what perspective would you offer a family member?

Monique Owens (17:50):

My perspective would be what I did was I asked questions. I had to first identify that there was a challenge going on and I didn't know how to handle this. So I had to ask questions of other people, seek information. I had to accept what I found out. "Okay, this child, this young person has this mental health challenge and what can I do with that?" Then I sought out the support for them, for myself, sought out the proper medical, or the process that would help them through it. Then once I got through that, then I was able to share the knowledge that I got and I encourage them to share the knowledge too, and therefore, we can help other families. So that's what I always will say.

Ken Duckworth (18:39):

So active engagement in learning and asking. Melvin McInnis, you've studied a lot of people who are living successfully with bipolar disorder. Do you have any words of advice or perspective for a person who's given the diagnosis, but may not like the diagnosis or may have ambivalent feelings or negative feelings about it? I.

Melvin McInnis (19:01):

I think that there's an element of time that is important to recognize and I think that the empowering of the individual themselves to get information and to learn about it as much as they can. I do encourage people to read a number of books on it. Most individuals recently diagnosed who will have read Kay Jamison's book, An Unquiet Mind, is an excellent description of bipolar disorder, and also Kay Jamison's story and her journey herself through it, I make fundamental recommendations and that is to live as healthy as one possibly can and to have a good night's rest, to avoid substances and to learn as much about the illness as they possibly can.

We work with individuals in that learning process and many a person goes through a phase in their 20s where they struggle with the diagnosis and we share their frustrations. They have a number of different challenging discussions with us and challenging discussions with their families saying, "This is not happening. I'm much better now. I can stop my medications." It's really a difficult position to be in to say, "You really do need to take your medication," when they're really not experiencing symptoms at that moment. Kay, in her book, she talks about the fact that taking that lithium tablet reminds her of the fact that she has this illness and she found that just incredibly difficult.

The education process varies, it's personal for each individual, but it's incredibly rewarding to work with someone through that process and to get to the point where they're thriving. We had some individuals in our program a couple of years ago and he said, "Listen, do not take bipolar disorder, overall, away from me. I don't want to have another manic episode or another depression, but I particularly like who I am and I want to be who I am and this is who I am. And I'm very proud of who I am and I like who I am." It's very rewarding to work with somebody into that stage of their lives.

Ken Duckworth (21:14):

This isn't their whole story, but this is a part of who they are.

Melvin McInnis (21:17):

It's a part of they are at the individual with bipolar disorder, has often, perhaps has a little bit of a different way of reacting with the world. In many instances, they've got a little bit more energy or they've got a little bit more creativity, but they contribute so many wonderful and amazing things that are energized and put a different spin on the way that we see humanity and humanity would not be what it is without individuals with bipolar disorder.

Ken Duckworth (21:46):

You mentioned Dr. Kay Jamison. One of her books reviews the artistic creative temperament and mood disorders in general.

Melvin McInnis (21:56):

I asked her about Robert Lowell, the poet that she wrote about, and I asked her, "Do you think that Robert Lowell would have been the poet he became without being bipolar?" She paused for about five seconds and said, "Nope, it was integral to his poetry and his writing and the energy and the insights and the creativity that he had." It's really important to us to appreciate that just because one is bipolar, it doesn't mean that one is a poet or an author or a musician. I had one of my colleagues that I worked with over the years inform me that it was really sometimes a bit of a problem because when people learned that she was bipolar, they thought, "Oh, you're really creative."

She says, "No, I'm not. I'm most creative when I'm well, and I want you to keep me well. I do not want to have any of these awful episodes," but that's where my creativity works. So it emphasizes that in every so many ways. The personal experience of the illness that really goes into the points that Monique and Marleyna mentioned was that it's important to know the individual. It's a personal experience. It's unique to the individual. It's unique to the circumstance. The context matters. The family member matters. The circumstances matter and time matters.

Ken Duckworth (23:07):

So following up on that perspective, I wanted to ask each of you how you've approached this problem in real time today and how that's different than, say, a decade ago when this wasn't as clear to you in terms of your learning and awareness? Marleyna?

Marleyna Illig (23:26):

How I approached things a decade ago, it was really all-or-nothing with me. It was very much, "If I don't get what I want when I want it, I'm not going to work for it." I didn't want to put the steps in to take care of myself and to do what I needed to do to better my future. Something really big for me that I've really been working on and building on the past year has been self-care, which has turned into self-love. Very simple things like brushing my hair, brushing my teeth, taking pride in my appearance, as well as getting used to schedules and making sure "Hey, I'm setting my alarm clock so I know this is what time I take my meds. This is what time I wake up. This is what time I get this done today."

Marleyna Illig

Even something as small as reminding me to call my grandma at this time, those are all steps I take that keep me consistent. What I've really, really learned is baby steps and something interesting is that I attempted to take my life 10 years ago and one of the doctors at the psychiatric hospital I was staying at had told me, "You're the type of person that you see the apple and you want to just swallow the apple whole, and you don't realize that you have to take bites from it in order to consume that apple." Something that has been really significant for me is learning to not try to just swallow the whole apple, but take the bites, take the baby steps.

Ken Duckworth (25:00):

What a great perspective. So it's really embracing the process, the steps, both of self-care and identifying your risks and also mitigating stress.

Marleyna Illig (25:10):

Absolutely.

Ken Duckworth (25:12):

It's sounds like it's been an important journey for you. Monique, what would you say your family has learned compared to, say, a decade ago?

Monique Owens (25:20):

Compared to a decade ago, my family has learned to listen to each other. We've learned to exercise empathy. We've learned to teach lessons based on empathy. Whereas, we used to be short tempered with each other, we will pause now and say, "Okay, now is this a challenge that they're having right now? Does your action help or hinder the process?" But teaches us to be able to slow down and think about what we're doing to contribute to that situation.

We're learning to step back and go, "Okay, I see what's happening. I apologize. How can we work through this together?" We're doing that on a consistent basis, generationally, with my children. They're learning, as adults, how to communicate with each other differently. Now we're bringing in significant others into our family and I take the time to talk with the potential significant other and say, "Hey, these are the challenges that we're dealing with. Can you handle that? And if you can, that's great. If you cannot, let's not create more problems."

Ken Duckworth (26:33):

Very upfront ownership, "Here's a vulnerability that we happen to have; we have a lot of strengths too. Is this something you're for?

Monique Owens (26:44):

Exactly. You give them the choice to be able to deal with it. They'll come to me and say, "I'm not understanding this process of what's going on with me. What do I do or how can I make it better?" It's causing other people to take an introspective look of themselves and it's causing everyone to be able to communicate differently. The goal is not to have strife all the time, every day, so let's try to figure out how we can adjust ourselves, talk better with each other. Everybody now wants to spend that time and help each other and we recognize when those challenges are taking place.

If she's having a moment, we all understand, and then we'll back off or we'll rally around and say, "Okay, how can we help you?" Sometimes the best help you can have is just to let them go, let them process through that. Now, when you know it's teetering on danger, then we're going to step in. We're going to make sure that you're safe. We check in on her. We have her check in on us. I have created, at home, a safe place. So they all know no matter where you are, home is your safe base. So we make sure that if you're having a time where you're not getting enough rest come home. There's a room, go get you some sleep. Let's talk about it and then send you back on out. So this is where we're doing it differently 10 years later.

Ken Duckworth (28:09):

That sounds beautiful. Well, Monique, that's a beautiful perspective in terms of the culture you've created in your family and Marleyna, I want to thank you for sharing your own experience and what you've learned with the people who will be listening to this podcast. So I want to just express my gratitude to both of you for sharing, being vulnerable, with your stories and communicating to others how they can better manage a challenge that not everyone finds easy to talk about.

Marleyna Illig (28:41):

Thank you. I'm always so honored and humbled to be able to do that.

Monique Owens (28:47):

Yes. I love being able to share and help other families and thank you for the interview.

Ken Duckworth (28:51):

I want to say this was a beautiful conversation with a lot of important recovery-oriented nuggets. I want to thank you all for listening and I look forward to other conversations where we learn from people who've lived successfully with serious mental health conditions.

Voiceover (29:09):

That's all for this episode of The Medical Mind. Look for the first part of this discussion led by Dr. Duckworth in The Medical Mind episode list. Tune in next month for a special series on major depressive disorder. The mission of SMI Adviser is to advance the use of a person-centered approach to care that ensures people who have serious mental illness find the treatment and support they need. Learn more at smiadviser.org.