

Personal Perspectives on Bipolar Disorder (The Medical Mind Podcast)

EPISODE 2

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 AM to 6 PM Eastern Time, Monday through Friday. To receive 24/7 crisis support, please text N-A-M-I to 741741 or call the National Suicide Prevention Lifeline at 800-273-8255.

This episode is the second in a two-part discussion about bipolar disorder. We continue the conversation with Dr. Ken Duckworth right where we left off in episode 1.

[00:37:09] **Ken Duckworth:** I want to ask Marleyna and Monique about your cultural identity, whether that's racial, religious, sexual orientation, whatever it may be.

[00:37:22] How has that factored into your experience, or has it factored in at all?

[00:37:28] **Marleyna Illig:** 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 nonwhite 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 the church. 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, a lot of times people want to stop it. Like, no, you need to continue taking it. That was something I didn't realize was so unusual to speak about in that community.

[00:38:50] So, while I've never had issues with it, I never realized that there is a particular stigma in that background.

[00:39:00] **Ken Duckworth:** What do you think has been your experience within the church?

[00:39:05] Do you feel like it's an area that the people want to talk about or is there still shame about it?

[00:39:13] **Marleyna Illig:** I've never experienced anything negative with it, but my brother had actually taken his own life when I was 14. 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.

[00:39:55] I'm really fortunate for that.

[00:40:00] **Ken Duckworth:** It sounds like your challenges began about the same time you lost your brother, if I'm understanding correctly.

[00:40:08] **Marleyna Illig:** I ended up in the hospital for the first time for a suicide attempt a month after my brother took his life. So yeah, it was at the exact same time.

[00:40:17] **Ken Duckworth:** Incredible trauma. Could your family talk about it then, that particular issue? Because many families have struggled to talk about a loss like that.

[00:40:28] **Marleyna Illig:** 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.

[00:40:47] **Marleyna Illig:** 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.

[00:41:05] **Ken Duckworth:** Boy, there's a lot, a lot of pain there.

[00:41:23] **Ken Duckworth:** Monique, what about your cultural identity? Has there been any impact of that on your experience or not so much?

[00:41:34] **Monique Owens:** Interestingly enough, it really has. We're of 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. I started seeking help because I realized that what was happening was much more than just typical teenage or children 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. And I said, if I pray anymore, Jesus himself is going to come down here, okay? And say, can you chill. And 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's happening.

[00:42:48] **Monique Owens:** It's something else. It's not what we were taught, this is not typical.

[00:42:57] So, because I've always felt it was something else, I kept trying until I found out what it could be. When the first one of my kids got diagnosed with ADD, I said, Oh, I'll take that. Okay, great. I like that and they were looking at me like, why are you accepting that? I said, because I have an answer.

[00:43:26] We came out of the church for years because I felt like I was not getting the 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 really got into NAMI and started understanding. I 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 happened. And I said, Oh, well, did you check to see if this could be the problem?

[00:44:07] 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.

[00:44:53] **Ken Duckworth:** I think I should acknowledge that the psychiatric establishment or profession has a history of misdiagnosis and over diagnosing African Americans. That has contributed to some of the lack of trust. I just want to acknowledge that.

[00:45:14] **Monique Owens:** That is very true. They're scared, 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.

[00:45:26] I said, look, I'll take the label if that's going to help my child. But that was my perspective.

[00:45:33] **Ken Duckworth:** 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.

[00:45:48] **Monique Owens:** I did, because the pain was too great that we were feeling and we needed some answers. We needed relief.

[00:45:59] I found that it was generational. 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 my son 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.

[00:46:33] **Ken Duckworth:** 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 increased for mood disorders.

[00:46:45] But, I want to ask Dr. McInnis a little bit about a common question I'm asked: my family member has bipolar disorder, what does that mean for me genetically?

[00:46:54] **Melvin McInnis:** 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 US 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 and parent, or an offspring, or just any distant cousin, there is an increased risk.

[00:47:33] Now, it's not a given that anyone in the family will have bipolar, nor is it 50/50. It is in fact about 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 of probability.

[00:47:59] So yes, one is at that increased risk, but it's 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.

[00:48:43] 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 in any one individual, may increase the risk. Now, there are other factors, and Marleyna pointed out the stressors and the context and so, there are many factors that contribute to the risk and genetics is one of them.

[00:49:19] **Ken Duckworth:** 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?

[00:49:33] **Marleyna Illig:** I think the thing that I would want to see the most of them is, just listen, 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. Treatment meds don't even work the same for everyone. It's really easy to just be like, well, this is how I handled this person at work for them. That's not how it's going to be with everyone.

[00:50:29] I feel like just really listening and working and kind of making it more tailored to the individual is what I would recommend the most. We're not all the same.

[00:50:42] **Ken Duckworth:** 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?

[00:50:54] **Monique Owens:** 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.

[00:51:22] 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'd let them know upfront, this is what's going on.

[00:52:14] **Ken Duckworth:** 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.

[00:52:33] **Monique Owens:** 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. And 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 up 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.

[00:53:13] **Ken Duckworth:** Dr. 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.

[00:53:31] Is there a research literature to support? To back up their experience?

[00:53:35] **Melvin McInnis:** 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. And I think 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, and the family and care providing team. I think that is a really critical element to that.

[00:54:10] 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 or treating individual can read it and can listen to it, but the law prevents them from revealing information about the patient themselves. Research indicates that the more information that the individual the treating provider has, the better that they are able to prevent the recurrence of illness. 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.

[00:55:19] **Ken Duckworth:** Their experience is really backed up by the scientific literature, it sounds like.

[00:55:26] Marleyna. I want to shift gears and ask you what you would advise somebody, who is recently given the diagnosis of bipolar disorder and might have complex or

ambivalent feelings about that. Based on what you've learned, Marlena, what might you offer to them from your vantage point?

[00:55:47] **Marleyna Illig:** 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. 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 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.

[00:56:44] 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.

[00:56:52] **Ken Duckworth:** That's a great message, Marleyna.

[00:56:54] Monique, for a family that has come to learn that their child or teenager or young adult, when typically the diagnosis is made, what perspective would you offer a family member?

[00:57:12] **Monique Owens:** My perspective would be... what I did was, I asked questions.

[00:57:19] 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, you know? Okay, this child, this young person has this mental health challenge and what can I do with that? I sought out the support for them, for myself, sought out the proper medical or the process that will help them through it. And 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. And so, that's what I always will say.

[00:58:05] **Ken Duckworth:** Active engagement in learning and asking.

[00:58:12] **Ken Duckworth:** Dr. 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?

[00:58:30] **Melvin McInnis:** I think that there's an element of time that is important to recognize. 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 will have read Kay Jamison's book, *An Unquiet Mind*. It's an excellent, excellent description of bipolar disorder and 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, have a good night's rest, avoid substances and learn as much about the illness as they possibly can.

[00:59:23] And we work with individuals, in that learning process and many a person goes through a phase in their twenties 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. You know, 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. And 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.

[01:01:00] 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.

[01:01:51] **Ken Duckworth:** This isn't their whole story, but this is a part of who they are.

[01:01:54] **Melvin McInnis:** It's a part of who they are and, the individual with bipolar disorder I'd say often perhaps has a little bit of a different way of reacting with the world. 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 and 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.

[01:02:30] **Ken Duckworth:** You mentioned Dr. Kay Jamison. One of her books reviews the artistic creative temperament and mood disorders in general.

[01:02:47] **Melvin McInnis:** I asked her about Robert Lowell, the poet that she wrote about. 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.

[01:03:15] It's really important to also appreciate, that just because one is bipolar, it doesn't mean that one is a poet or an author or a musician. One of my colleagues that I worked with over the years and informed me that it was really sometimes a bit of a problem because when people learned that she was bipolar, that, 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.

[01:03:45] But, you know, that's when my creativity works. So, it emphasizes that in ever so many ways, the personal experience of the illness. That really goes into the points that Monique and Marleya mentioned, 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, circumstances matter, and time matters.

[01:04:20] **Ken Duckworth:** 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?

[01:04:39] Marleyna?

[01:04:41] **Marleyna Illig:** How I approached things a decade ago 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 and 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.

[01:05:11] It was 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, this is 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, 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 learned is baby steps. 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 that 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.

[01:06:22] 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 step.

[01:06:39] **Ken Duckworth:** 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.

[01:06:50] It sounds like it's been an important journey for you.

[01:06:54] Monique, what would you say your family has learned compared to say, a decade ago?

[01:07:02] **Monique Owens:** 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.

[01:07:16] Whereas, we use 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? It 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. I take the time to talk with a 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.

[01:08:23] **Ken Duckworth:** Very upfront ownership, here's a vulnerability that we happen to have. We have a lot of strengths, too. Is this something that you're up for?

[01:08:34] **Monique Owens:** 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 them. 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.

[01:09:30] Everybody now, wants to spend that time and help each other. We recognize when those challenges are taking place. Like, 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? And 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.

[01:10:06] 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 and so we make sure that if you're having a time when 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.

[01:10:36] **Ken Duckworth:** That sounds beautiful.

[01:10:47] **Ken Duckworth:** 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.

[01:11:03] 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.

[01:11:20] **Marleyna Illig:** Thank you. I'm always so honored and humbled to be able to do that.

[01:11:25] **Monique Owens:** Yes. I love being able to share and help other families. Thank you for the interview.

[01:11:33] **Ken Duckworth:** I want to say this was a beautiful conversation with a lot of important recovery-oriented nuggets.

[01:11:41] 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.

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.