HEADS UP!
Community Mental Health
PODCAST

Chris Summerville, Katrina Tinman, Dr. Phil Tibbo Interview Transcript

RICK 0:10
Welcome to the HEADS UP Community Mental Health podcast. Join our host Jo de Vries with the Fresh Outlook Foundation, as she combines science with storytelling to explore a variety of mental health issues with people from all walks of life. Stay tuned.

JO 0:32
Hey, Jo here. Thanks for joining me and my three guests as we learn about schizophrenia, perhaps the most misunderstood and stigmatized of all mental illnesses. In this two-part podcast brought to you by the Social Planning and Research Council of BC, we'll explore the challenges experienced by people with schizophrenia, and the proven opportunities for healing available to them. We'll hear from three remarkable people who are devoting their lives to the cause.

First, a woman with decades of lived experience, who is now helping others along their own recovery journeys. Then, the executive director of the Canadian Schizophrenia Society, will share his personal and professional observations about recovery, and needed systemic change. And finally, a clinical and research psychiatrist will share past, present, and emerging diagnostic and treatment strategies, along with his thoughts about recovery philosophy. But before that, let's connect with Rick our researcher to learn the basics.

RICK 1:37
First off schizophrenia is not a single distinct illness, but instead a psychiatric diagnosis with various symptoms found on the schizophrenia spectrum. There is no single lab test or brain scan for schizophrenia. Doctors will explore symptoms on the spectrum if there are no medical conditions, mental illness, or substance-use issues that could be causing signs of the illness.

JO 2:04
What symptoms are doctors looking for to confirm a diagnosis of schizophrenia?

RICK 2:10
Symptoms are classed as positive, negative, or cognitive. Positive, or psychotic symptoms include hallucinations and delusions. These occur when a person loses touch with reality and must be present for a diagnosis. Negative symptoms indicate lost capacity, such as social or occupational dysfunction, or a lack of hygiene, expressiveness, or motivation. Cognitive symptoms affect thinking processes, and can impair concentration, memory, judgment, and decision-making skills.

JO 2:49
Who's most affected by schizophrenia?

RICK 2:51
Symptoms are typically first recognized in the late teens and early 20's. While boys are 40 percent more likely than girls to be diagnosed, girls are more likely to be diagnosed at an older age.

JO 3:06
Do we know what causes schizophrenia?

RICK 3:08
While potential causes are still unknown, experts agree that several vulnerabilities can set the stage including genetics, prenatal infection or birth complications, abnormal brain structure, chemistry, trauma, cognitive impairment, and environmental stressors.

JO 3:29
Last question Rick, how widespread is the illness?

RICK 3:33
People from all geographies, races, cultures, abilities, genders, and socio-economic groups have the illness. About one percent of the world's population is affected. That's about 80 million people worldwide, or about 380,000 in Canada.

JO 3:52
Thanks Rick, it's certainly a big problem with serious implications for individuals, families, workplaces, communities, and certainly our mental health care systems. For more information, you can visit the Canadian Schizophrenia Society at schizophrenia.ca.

I can't wait to dig in deeper with our guests, the first of whom is Katrina Tinman, a peer support worker at the Mental Health Crisis Response Center with Peer Connections Manitoba. Welcome Kat, and thanks so much for joining us.

KATRINA 4:29
Thanks for having me. It's a pleasure to be here.

JO 4:32
Later, we'll explore the stigma and discrimination faced by people with schizophrenia. But for now, I'd like to share my own story of stereotyping. Until I met Kat and her colleague Tracy Kosowan, I'd never spoken to anyone with the illness. My only experience was seeing people in my community who I knew were affected. Some walked fast, their faces expressionless with eyes focused straight ahead. Others talk to themselves. One fellow always carried a stack of books, while another always wore headphones and the same dirty clothes.

That was the extent of my understanding about the illness. Then I learned about Kat's life and read a speech Tracy wrote. My first thought was just how difficult their journeys have been, and how amazingly resilient they both are. I don't know that I would have been so able or determined to recover if I'd been in their shoes.

Mostly though, I was struck by the fact that they're just like me, women with mental health challenges who've learned to manage their conditions, their work, their lives, and their dreams in meaningful and productive ways. So Kat, let's open with your incredible story. Where's the best place to start?

KATRINA 5:49
You know, it took a few twists and turns. It started though, as just an average kid, growing up middle class, Can-American in my case because I'm a dual citizen. That was the one unique thing about me. I'm a dual citizen of Canada in the United States. And as I progressed through schooling, I did very well, even was one of who's who in American high school students, as I was studying high school in the United States. Attended University of Fargo, North Dakota and graduated in 1998 with a degree in journalism and political science. That took me to about the age of 25.

And that's when things started to change. Now not really right away, because I met, married, and fell in love with somebody, not necessarily in that order, and became a sales and marketing director for a pool set company actually making pools accessible for elderly and disabled. I traveled, skied, rode motorcycles, camped, played Texas hold'em poker, and even scuba dove. I was living the life, as my cousin once said, and never expected what was coming my way.

But there were a few things that didn't pan out. And a few things that were kind of negative. By 2003, I started to experience symptoms that others noticed. I'd say it this way, because I never recognized or realized myself that I was getting sick in any regard. I just knew people were telling me, "oh there's something wrong" and, "might be a mood disorder." Though they were never certain back then what was going on in my head. In ways, neither was I.

It's a very sneaky thing at first. I just didn't see it. And I should have realized the potential. But that's hindsight because my mother actually had illness before I did. What got me though, was mental illness, it's not a genetic absolute, and that I always knew. So I didn't get how I had it, and didn't see the absolute and I wasn't seeing it myself. I went through my many experiences from 2003 'til present, and actually define I had two different journeys of recovery.

The first one concluding coming to a climax point in 2009, where I had reached a point of going from being examined and not really recognizing, realizing it, and starting to get it, I guess, that in 2009, the doctors actually said, "well, you can go off medications, your insight is strong enough, you're aware."

A lot of things changed for me in 2009. I divorced my now ex-husband, and I no longer was employed. And that presented a lot of stress. And I ended up not recognizing or realizing it again, because I still was at the point of not acknowledging illness. I actually thought it was just because my marriage turned out to be a bad one. Discreditation of me, I thought it was just trying to write me off, make me not count, make my voice not heard, and things of that nature.

In 2009, those stressors really served to trigger me. And it was retrospectively, I can say it now, at the time I couldn't, I didn't think it was me. But in 2009 in July, I was starting to really get sick and go on that journey. And because, at the time, I was so immersed in my divorce and some of the other things of trying to find a job in an economy that actually was taking a massive hit in 2008 and 2009, I still didn't see it. And I actually moved myself from Fargo, North Dakota where I was residing to Tucson, Arizona in search of a job. Even that decision might have been a sign of my illness at play in a way and I just continued straight downward in a long, slow spiral.

By 2010, my economic assistance, unemployment, had run out and I was no longer able to maintain housing. It just collapsed more and more and the illness did reveal. But it's retrospect that shows me that at the time, I didn't really realize. That's one of the things about the illness. It's like this betrayal from the inside out. You can't believe what's inside.

By 2010, I basically went back to Fargo, North Dakota with assistance from somebody. But things were still getting worse and worse and worse. My decision making was horrible. It really was. Even my choices in partners were based in unreal things in ways. And I still, up until that point, didn't see it. By 2011, I actually left Fargo and came back to Winnipeg, where I was born, and just tried to survive, still not getting it. By 2013, though, I was actually already at the point of homeless because that was from 2011, through on again off again in very assorted ways, and in hospital. Somebody actually cared enough to look at me and say, "No, there's something here."

And it started to sink in. But not until about 2012, 2013. I went that long a time. Not getting, not seeing, not wanting to either. There was one particular instance, a former roommate saw me on the street. I converse with him briefly and he right away said, "Are you okay? Are you sure you're okay?"

There was an instance where I'm trying to take a moment to feel human in the midst of homelessness. I went into a dress shop to try on a dress. And it did hit in the back of my brain as I looked in the mirror at myself and saw what I had become, which really was not good. I had shrunk from being a size 14 and 2009ish to being a size six by end of 2009, down to by 2012 when I was homeless, I was shrinking down to zero. It was like I was shrinking away to nothingness.

Now, that's a lot to take in. But there was still hope. And that's what actually got me. There were a few instances over time of help that came my way. And I think I started to recognize that. And, it's not easy saying it but I ended up in hospital involuntarily. But it was because somebody cared enough to call. And there was enough evidence of it. It wasn't because of the want to harm self or others that wasn't present. But the detriment to self was really there. For all of it. I never had suicidal ideation. But there was definitely enough evidence of illness present.

I was having hallucinations. I was having delusions. My cognitive impairment was definitely present. It was all of it. And once again, it took a lot out of me because when I was a kid, I was nothing like that. I made it all the way through university, attaining exceptionality in grades, and doing well and juggling multiple jobs to get her done. In conjunction with financial aid, I was able to work for a decade actually being a sales and marketing director. But in that journey of recovery there was some semblance of support system, while I was married.

Now the hard part was that marriage end and that transition. My parents, they had actually reached a point where they were no longer together, and they were both at retirement age. And they didn't have a way to support me and give me that help. And I was residing in an area that didn't have much social structure for agencies to help. And I moved to another area that really didn't have anything that I could find easily. But in the midst of it all, I wasn't looking because I wasn't seeing that I was sick.

And it wasn't until 2013, that really, it came about in a hospital. I was actually walked through some of the questions, now what are the berms? And it was something that I realized, oh no, you're asking me that when the berms were something, and that moment I realized were something unreal. And to this day, I wish I could thank those doctors. Just saying in those moments, you can say they saved me.

There's so much more that I could encapsulate between 2003 to 2013. Because one of my stories includes hitchhiking across two countries, lost. Still kind of survived, but I was truly lost.

The education was wasted. Those four and a half years I spent obtaining a degree with two areas of focus, that was out of the window.

When I was released from hospital in 2013, I did finally have network, I had a social worker, a mental health worker. And at discharge, it was first a question where to get housing. I took what was available, which was actually the Winnipeg Hotel, which was a dive hotel. Only had one incident there that was unpleasant, and ended up there for a year, and then was able to get into housing. And that was beginning of 2014.

That same timeframe, the social worker, after engaging me for a while and trying to pick my life back up from being at that bottom point, he actually had this broad sheet of information about some of the agencies that Winnipeg had. And it was at that point, I kind of reached a juncture of where do I go. Because at that point, I finally had a diagnosis.

What originally started in 2003 as just well, mood disorder, we don't really know what's going on, mood disorder, we'll just call it that. Because it's a mood disorder, we know that it had evolved. And by 2013, it was schizoaffective disorder, which is the traits of schizophrenia and the traits of a mood disorder, in my case bipolar.

That still kind of left this trick of where to go, because the agencies that I found were very illness specific. But I found the Manitoba Schizophrenia Society, and Chris Summerville actually. I actually first met, though, a woman named Karen who worked for the organization. And she kind of introduced me to what it stood for and what it was about and what help might be. I started using that opportunity.

Something had shifted in myself in 2013 and 2012 end point, where after going through all of it, which included the self stigma even, I turned around on myself and re-embraced myself and said, "Well, I'm still human, I'm still me. And okay, so there's this illness point, but it can be dealt with just like mom dealt with diabetes." And I was able to turn things around and started going to the Schizophrenia Society, and then falling for it in a way of deciding, well, this might be a good place to volunteer, and pay back all that I had acquired through social structure and help in other regard.

And I progressed and stayed a volunteer until the beginning of 2015 and was at that moment able to become an employee. Now 2014 is when I was able to move into housing, that was actual housing. It took a year, though, for things to really flush out where I could look for a job again. And yes, in 2015, the Manitoba Schizophrenia Society offered me that opportunity.

JO 19:21
Thank you for sharing Kat. Your incredibly compelling story is the reason that we do this podcast. I'm so blown away by your resilience. Can you tell me where you think that comes from?

KATRINA 19:35
I really think it comes from my parents and how they raised me. I don't know beyond that, something else inside me, my faith and hope that I found the beauty that still surrounded me that I could still see. A psychologist in my early recovery journey, once spoke with me and the psychiatrist both, about how the truth is still in people. And there's still all those parts of reality there. It's just kind of piecing it back together again.

JO 20:09

So how do you support yourself, or what do you tell yourself, during your most challenging moments?

KATRINA 20:16
I remind myself that I've already done so much. I take a look at all that I have done and realized, not many could. Because I look around and there's so many who are there, and are not doing it, and are not getting out of it, and are still in their places and spaces that are more difficult for new people venturing into those spaces. I actually am now at this point where I'm turned around so much toward it, to facing it, that it's a deep core value. And that's the peer support part of me that I am now doing, and that work to reach back out and help others, and that feeds me.

JO 21:08
How did your schizoaffective disorder impact the relationships you had, and now have with your family, friends, and colleagues?

KATRINA 21:18
It's an interesting situation in many regards, because it depends on so many factors for each one. In the instance of family, it was intense conversation and misunderstandings. At one juncture in my journey, I was in Tucson, Arizona with my dad's sister and her husband, my aunt and uncle. And I was really raging leo. I kept turning off the swamp cooler for their air-conditioned Tucson, Arizona home. And that is actually the worst thing you can do for a swamp cooler. And they couldn't understand that it was actually part of my delusion. And I couldn't understand their point of view, because I was in the midst of my delusion. And so, we had various different, difficult situations and conversations to the juncture that they said at that point, I couldn't stay with them, I had to go to my Dad.

Now this was actually at a point in time when I was homeless. And on that hitchhike, I was in the States at that point in time as was my Dad was moving to Denver. The short story is I didn't connect with him. I ended up back in Winnipeg in a longer term. But there's other relationship issues, the interactions between significant others and myself. Those are always charged with it, with a fear that can impact me now, how is this person going to react to me, and respect me, and treat me.

I've had situations where there wasn't the proper treatment, where I was actually healthy and accused of being mentally ill for being in an argument with a person, when they were themselves being out-of-line and inappropriate. A big day before a big event of my life, where one would have thought they would have been more supportive. And yeah, we are arguing and that came out of them instead. That uncomfortable, "Why are you mentally ill?"

I've had situations of being assaulted, and the illness being used as an excuse. I've had situations of, my current partner might be a keeper. Because I have had situations because my medication doesn't cover all my symptoms perfectly. And I've had medications, well we're worse. This one is actually really good. But it doesn't cover everything. And once in a while something pokes through. And this partner, he's actually been on his own journey and understands in a different way, how things can happen, and illness can happen. And he embraces me in a different way. So now, I'm possibly in a positive situation.

JO 24:21
How much of your story do you share with peers or the people you work with? And why do you think sharing your lived experience is helpful in their recovery?

KATRINA 24:31
I try to share what is most applicable to their story and situation. Because ultimately, the sharing is supposed to be relevant for that peer as they're going through their process and conversation. Oversharing is not what it's about. It's part of my training actually, to look for that fact and to be aware of that potential. Because the peer is the ultimate focus of the interaction.

It's appropriate for sharing in creating connectivity between myself and the peer and being able to share with them that feeling that they're not alone. And that reinforcement that they can do it, and that validation that they might be lacking. So, it really depends on the situation. Sometimes there is very little sharing. Sometimes there's more.

JO 25:24
As mentioned earlier, the Schizophrenia Society of Canada is a great source for information, inspiration, and mobilization. I now have the pleasure of introducing Chris Summerville, the society's Executive Director since 2007, who has amazing insights that reflect personal and professional experiences with schizophrenia over 50 years. Chris earned a doctorate from the Dallas Theological Society, is a certified Psychosocial Rehabilitation recovery practitioner, and an adjunct professor at Brandon University in Manitoba. So glad to have you here, Chris.

CHRIS 26:06
Thank you so much, and what a pleasure to be joined with Katrina and Dr. Tibbo in making this podcast.

JO 26:13
We're so happy to have you here Chris. We'll dig into your perspectives as a recovery practitioner and society leader slash advocate a little later. But first, please tell us about your family's experiences with mental health challenges in general, and schizophrenia in particular. And when did your focus on schizophrenia change from being personal to professional?

CHRIS 26:40
Well, as you've heard Katrina's story, it's definitely not just an individual experience, but it is indeed a family experience. I mean, the family is involved in all the trauma, and the burden, and the suffering, and dealing with the complexity of having a mental illness. For the Summerville family, my mother, seven of her seven children had significant mental health problems. We lived in a very, what used to be called a dysfunctional home, a very unhealthy home, and that certainly did not help us in dealing with the mental health problems and the mental illnesses.

My father struggled with what we would call today, bipolar disorder, along with alcoholism, addiction issues, as did a brother Dennis, who struggled with the same thing. And both of them took their lives by suicide. It was just difficult for them to continue on and had lost all hope that things could get better. Then my other brother Terry was in Vietnam, and he developed cannabis-induced psychosis, and also struggled with addictions. And both of those two brothers spent time in prison. And I myself as a teenager, I struggled with what's called today, depersonalization derealization, along with depression. And basically, it's sort of like an out-of-body experience, and you're not sure you're in reality. And it's very scary, and you feel very lost as if you're a rimless bubble on the sea of nothingness.

That's a sort of an existential thought, even for a teenager as I was to be trying to figure all of this out, which I indeed was trying to figure it out. But in those days, we didn't talk about mental health, we didn't have words for it. We literally didn't have words for it. And so, it was the shame of the family that bound us, there was really no hope. Even as an adult, periodically, I would struggle with depression, along with suicidal ideation, and never, quote, attempted to take my life. But having noticed suicidal ideation and the fear of hopelessness and living the secret because you didn't talk about it, you don't talk, you don't feel, and you don't trust. And that in itself was a great bondage, so to speak.

Then I pastored for 25 years, I started when I was 17, and I struggled with it. But I remember when we moved to Niagara Falls, Ontario in 1985, my wife and I, at that particular church there, I was addressing mental health issues. I was kind of an unusual pastor in terms of the fact that I would speak occasionally about my experience, and was very conscious about individuals that were part of the church that I pastored that they were struggling, not just with spiritual issues, but also with mental health issues.

Unfortunately, the faith communities not really address mental health issues as they ought to. I mean, they're certainly getting better at it. But during those days, in the 1970s, 1980s, and even the 1990s, it was rare for a pastor, number one to be vulnerable, and number two, to address it in a forthright manner.

As I progress with my story 22 months ago, when I'm 68 years old, I had a hospitalization. It was actually my first hospitalization. I had been struggling with depression and anxiety, and my psychiatrists had put me on a new antidepressant. And I had serious side effects, very, very serious side effects, as if I were having muscular seizures, inability to concentrate, the anxiety getting much worse. And so, I was admitted to a hospital voluntarily, but under the Mental Health Act. That was all very scary, because unfortunately, to be a patient in a psychiatric center is not pleasant.

Unfortunately, many service providers treat you as a diagnosis as opposed as a person. To answer the question about moving from it from a personal or professional aspect, like I said, I did address it as a pastor. The response was very hesitant. People weren't comfortable about disclosing. And that was very sad to me. And many people would deny not because they lacked insight, but because they were ashamed. And it was embarrassing to be so vulnerable and open about it.

In 1995, I made the transition from the pastoral world to the mental health world, because I wanted to work more closely, and to be a strong advocate, and to be a voice for those who are voiceless, and to see transformational change in the mental health system here in Canada. So I began with the Manitoba Schizophrenia Society in 1995, was there for 25 years. Also, during that 25 years, in 2007, I became the CEO of the Schizophrenia Society of Canada. It has been a pure joy. It has afforded me to be a leader of leaders.

I often think about Martin Luther King, not that I'm in the same arena as he is, but I grew up in Birmingham, Alabama. I know what racism looks like, because I was a racist, and learned myself out of it. And also, my spirituality helped me to move towards seeing people and not labels, in color necessarily. To be able to take my lived experience, and not only bring hope and encouragement to individuals and families, but also to be able to engage, along with Katrina and Dr. Tibbo, being at the tables where decisions are made by different levels of government, and to represent the voices of those with lived experience, and in the family lived experience, and to create a better mental health system in Canada.

JO 32:37
Another amazing story Chris, thank you so much. Can you tell us more about the evolution of your brother's experience with schizophrenia?

CHRIS 32:47
Well remember, it was 1964 when Terry developed cannabis-induced psychosis. And the reality is if he were living today, his outcome would be better today. There was no understanding about early intervention. So, he went for years without any assistance or help. There was no access to psychiatric or psychosocial rehabilitation. So once you began to get quote, help, that help was very limited. It was basically take these medications to reduce symptoms and go home. You won't have any friends; you probably won't get married. It was a sort of a kiss of death diagnosis, so to speak. And recovery, good grief, very few people and very few service providers were even trained, let alone talked about the possibility of recovery, which we can define later.

And as far as addictions, no one addressed the addictions. And we now know that they both should be seen as primary disorders in terms of a mental illness, and a substance-use problem. And then both have to be simultaneously treated because one influences the other. There was no family education. Insight into having any understanding about mental health and mental illness was zero for ourselves. And so, I'm absolutely convinced that if my brother were developing schizophrenia today, that his outcomes would be a lot better in the process.

He lost his physical health, developed cirrhosis of the liver, he lost his family, he never saw his grandchildren. He was sort of ostracized by everyone. Those losses were profound. And it wasn't just because he had schizophrenia, the wall, there was a giant wall like he was on the other side of the wall, and we were on the other side. And that wall was not just the schizophrenia, it was stigma. It was self stigma. It was loss of identity. It was the lack of early intervention, psychiatric rehabilitation and recovery, mental health services, the lack of addressing the addiction, the lack of hope that created this huge wall barrier.

And we basically had no way of understanding as family, how to tear that wall down, and he on the other side of that wall. I mean, Katrina is much, much, much more informed, as you've heard her story. It doesn't have to be that way today. What my brother experienced, that doesn't have to happen today. But unfortunately, it still does in areas of Canada.

JO 35:31
How is your brother now?

CHRIS 35:32
He is actually still living in a veteran's home, sort of a ghetto. It's a slum, which breaks my heart again. His health is reasonably good. He doesn't struggle with psychosis. He's on medication. But my aggravation and my grief is that that's all he's gotten really is medication, as opposed to all the kinds of supports, and just even a decent place to stay. And I have gone down to the state to try to help, but they know I live in Canada. And so, my advocacy efforts have always been very limited.

JO 36:08
Can you tell us more about the relationship you have with your brother, and the personal insights you've gained over his five decades with this illness?

CHRIS 36:18
We have a good relationship. We both have a strong sense of humor, which we got from my mother. And we utilize that in terms of maintaining our relationship. He knows that I care from my heart. And I think listening to him and being able to empathize with the emotions that he

feels. You shouldn't agree with the content of the delusions or hallucinations when one has them, but one thing you can do is come alongside of the person, and affirm, and confirm, and validate the emotions that they may be feeling as a result of those delusions or hallucinations. And that's therapeutic. And in fact, it lessens the angst and the anxiety that the person is experiencing when you are able to do that.

The fact to, I don't argue, I've never argued with the illness. Well no, that's not true. I had to learn not to argue with the illness, which many families do, to see him a person and affirm him in terms of his expressed desires. Another thing I learned was not to always focus on the mental illness, but to ask him questions like you would have any other person about his hopes and dreams. I think the fact that I did not abandon him, I did not isolate from him, but have attempted to maintain a relationship with him over all these years. I know he's appreciative of that.

JO 37:38
Such profound insights Chris. We'll bring you in again after we hear from our next guest, Dr. Phil Tibbo, a Canadian psychiatrist who studies, treats, and advocates for people with psychosis and schizophrenia. Dr. Tibbo is also a professor of psychiatry at Dalhousie University in Halifax, Nova Scotia, and director of both the Nova Scotia Early Psychosis Program, and Early Psychosis Intervention Nova Scotia. Welcome Phil, such a treat to have you here.

PHIL 38:12
Well thank you, and it's great to be here. And thank you so much for having this as a focus for a talk and a podcast. It's very important and needed as well. And, of course, I have to echo Chris' comments too earlier, when he was introduced, that it is for me truly honoring to be sharing this mic with both Chris and Katrina here today.

JO 38:33
So let's start with the story of how you landed on the study, diagnosis, and treatment of schizophrenia as your psychiatric specialty.

PHIL 38:43
Great question. I think I have to sort of back up a little bit with respect to that in my journey. I obviously entered into medical school, and interestingly, psychiatry was the furthest from my mind when I was in medical school. I entered medical school because I wanted to be a sports medicine physician, and all my electives were in sports medicine. But then as I did my psychiatry rotation, it sort of tweaked on me that I actually truly liked talking with the patients, seeing some improvement, seeing the resiliency that's there, as well as the struggles and challenges and what I could do to help with that.

I subsequently did my rotating internship and then actually still wasn't quite sure what I wanted to do. So, I worked for one year as a family physician at the Nova Scotia Hospital, which is our provincial psychiatric hospital. And there I was responsible for the medical care of an entire unit, but as well as looking after the psychiatric needs of half of a unit as well. And interestingly my title, because I had those dual roles, the official title was whole person physician, which today still makes me smile because I realize and reflect on it, that's still my approach to the work that I do as a whole person physician.

That sort of cemented for me my desire to do psychiatry. And then it was during my psychiatry residency, my specialty training, and my rotations through interactions with individuals who were living with psychosis or schizophrenia spectrum disorder, that I realized that it was something that definitely interests me, again for the same reasons, sort of appreciating what the brain can do in this development of these delusions and hallucinations. But as well as working with the individuals to, and understanding them and how these delusions, hallucinations affect them, and how it affects the family and seeing, ok what is the possibilities here? How can we work this through and get somebody back on their feet?

And in some ways, the term you sometimes hear is a good fit. And that I really saw this as an area, for me, it's something that definitely interested me. I was fortunate in my last year of my specialty training to spend a fair bit of it down in Iowa, working with then the leading researcher in schizophrenia research, Dr. Nancy Andresen. And then that also cemented for me that I should be doing research in this area as well, because at that point, and still, you know, there's a lot of research that still needs to be done in many facets of schizophrenia, from understanding the illness, to treatments, and many other areas as well. And then that's what led me to my career. So, I've always been what we call a clinical researcher. So I'm a clinician, I do see patients, but I'm a researcher as well, within this area.

JO 41:30
Great story and thank you for all the great work you're doing. So, when you listen to both Kat and Chris' stories, what about those stories tweaked your medical mind and touched your human heart?

PHIL 41:46
Well, I like to say it touched my heart first versus my medical mind. But these are extraordinary journeys. And people that I talked to have these extraordinary journeys. And I think some of what I heard in both Chris and Kat, and that sort of leads me to the area that I work in with respect to early intervention services, is really the work that we need to do to understand this illness, so that we can identify illness early, and that we can treat early as well.

Our main goal really is to optimize an individual's outcomes. If we only are able in those situations to truly identify early, treat early, and have some of the resources that we have now would have been nice to have in the 80s, and in the early 90s as well too. But yes, amazing journeys that we're able to talk about today.

JO 42:36
Like to get down to a few nuts and bolts with regard to the illness. First, can you give us the Coles Notes history of schizophrenia's diagnosis, treatment, and prognosis? So really, then versus now.

PHIL 42:51
I'll try not to go into a full lecture on this. And also, I like the term Coles Notes. Some of, perhaps our younger listeners, may not know what Coles Notes are, but I'm fully aware of what the Coles Notes are going to university. I think, you know, with most things with physical health, mental health, we know these illnesses have been around for quite some time. I guess most people point to the evolution of, or the start of, more modern psychiatry, the modern sort of idea of schizophrenia and psychosis really started at the beginning of the 20th century.

The name that you will hear a fair bit is around at that time is Emil Kraepelin, who was a German psychiatrist. And he is really credited with truly writing about, and studying, and trying to understand what we know today as schizophrenia, and truly from a clinical perspective. And he was an individual who was able to understand or appreciate the difference between what we call today a primary psychotic disorder, and a mood disorder. And being able to write about that it's one particular symptom that is a diagnostic, but oftentimes, it's a pattern of symptoms that we have to look at. So, he coined the term dementia praecox, actually, as what we know today is schizophrenia. But then, over the years, that diagnosis has changed.

Another name you'll hear is a Eugen Bleuler, who a little bit later on, sort of broadened the concept of schizophrenia. But I mentioned his name because he was actually the individual that coined the term schizophrenia, that kind of splitting of the psychic processes like emotional and intellectual. So he coined that term, but from a diagnostic standpoint, it really wasn't until perhaps the 50s when the Diagnostic and Statistical Manual, the DSM, came into being, and that really allowed the field of psychiatry to have a unified way of diagnosing schizophrenia and schizophrenia-like illnesses.

And really that encapsulates criteria where if an individual presents in Canada, and an individual presents and another part of the world, if they use the DSM, then they would come up with a very similar diagnosis. And this was important, of course, within mental health because then and even today, we don't have one particular blood test that could make a diagnosis that you would get with some of our other medical illnesses as well. So, we are having to rely on a number of other different symptoms and factors to look at to diagnose.

So that's how the diagnosis has moved on. And the DSM has gone through a number of different revisions. We're currently on the DSM-5 as well. But the ideas and the concepts are there to have that unified approach for diagnosis of the various illnesses. That's around diagnosis. Of course, treatment has changed over the years as well. And I always say, how surgery was done in 1910, 1920 is different from how it is done today. And we have seen that evolution in time. But just to point out that from the medication standpoint, which really was a game changer for schizophrenia and psychosis, that chlorpromazine was the first medication, and that really wasn't developed and available until the 1950s.

But that was a medication that wasn't developed primarily for schizophrenia, or psychosis. It was actually developed as an adjunct medication for surgery. But the various properties and how patients were talking about how the meds sort of affected them, they decided to use it within and trial it within psychiatric and particularly psychosis population. And actually, if you read up a bit about chlorpromazine, you see sometimes the comparisons are made to antibiotics and infections and that. When chlorpromazine is used it wasn't more of sedative, but actually helped with delusions, and hallucinations. That's where we started seeing people actually being able to leave hospital.

And of course, since then, that was a proposal first medication, we better understand how it works now, and as a result, sort of more targeted approach to medication development. That's the medication side of it. But of course, and something that Chris alluded to, as well, it's more than just medication too. And you see that development over the years of other types of therapies, for example, of psychotherapies. We have to have a few tools in our tool chest with respect to that interesting development.

JO 47:05
We'll dig deeper into those treatment strategies in Part 2 of this podcast. But first, can you tell us about the similarities and differences between psychosis and schizophrenia?

PHIL 47:17
When I do some public speaking on this, sometimes I start with a bit of an apology, because I tend to use those terms interchangeably sometimes. And I think that's more of a reflection of the work that I do within early intervention services. And oftentimes a diagnosis is not clear. And as

a result, that we tend to use the word psychosis a fair bit. A psychosis itself is not a diagnosis, it's more of a set of symptoms. And schizophrenia, for example, is a diagnosis, schizoaffective disorders is the diagnosis, delusional disorder is a diagnosis. While schizophrenia is considered a psychosis, psychosis is more of a kind of a broader term and concept.

JO 47:56
What happens to people during psychosis?

PHIL 47:59
Well, it's very individual. There's not one particular sort of set of symptoms that can happen. But from a psychosis point of view, we often talk about grouping of symptoms. So, people can have what we call positive symptoms, which are not necessarily good symptoms. It's just that they're there, and they shouldn't be there. Those are the things like delusions, hallucinations, thought disorder. Then there's the negative symptoms as well, and those are experience or cognitions that should be there but are not. And that could be things along the lines of what we call alogia, sort of difficulty thinking, amotivation, difficulties in even just energy levels as well. A psychosis is also comprised of cognitive symptoms as well as mood symptoms too. But it's very variable for how people experience their symptoms.

JO 48:45
We may not know what causes schizophrenia, but we know it has distinct stages. Can you tell us more about that?

PHIL 48:53
Now that's a great question. I would say yes, we know, we defined schizophrenia now as having stages and we should be careful using the word distinct, because sometimes it's very difficult to know start and ends of particular stages within this. The different stages that you'll tend to hear first is really around, we talk about prodromal stages. Prodromal basically means by definition, one of the symptoms that are there prior to what we call frank psychotic disorders, before somebody could actually meet criteria for a diagnosis of schizophrenia. And that prodromal phase, again, can last a very short time for some people and very long for other people as well.

And oftentimes there are unfortunately kind of what we call nonspecific symptoms, but as well can be psychotic-like symptoms but don't meet the criteria for delusions or hallucinations. Again, early intervention services are focused on trying to identify really what those prodromal symptoms could be, but they're recognized as something that's different from what that individual use would be. And then we do move into the next phase, which is called early phase psychosis or first episode psychosis. And really, that's the first three to five years of illness in a very critical and important time, in order for us to address the illness and again maximize outcomes.

After we go through the early phase of psychosis, and there's different terminologies after that. Sometimes what you hear is either residual, or chronic. I don't particularly like the word chronic, because it has a negative connotation to it, but all really, truly what it implies is that it is somebody living with illness at that point in time. You can get into some of the more finer details of each of those, but those are more the high-level view of the various stages.

JO 50:29
What conditions can occur alongside schizophrenia?

PHIL 50:33

Having schizophrenia is not exclusionary for any other kind of illness. For example, for mental illness, people can have schizophrenia, but as well can also have a mood disorder, anxiety. Chris mentioned substance use as well, addictions. So, these are definitely possible and think that we from a treatment team has to be able to identify and treat if needed, as well. Oftentimes, we also have to make sure that some of those symptoms are not as a result of schizophrenia as well. Because sometimes we have to be careful making sure that we treat the schizophrenia as best we can to ensure that those other symptoms aren't there.

JO 51:11
So do you have to treat each condition separately then?

PHIL 51:15
You tend to yes. We want to make sure that our treatment of schizophrenia is optimized. I guess a good example of that would be if someone is having paranoid ideation, like feeling like somebody's out to get them, out to harm them in some way. Well, you expect them to be anxious. But that doesn't mean you have an anxiety disorder that's separate. So, you need to make sure that that is treated, those symptoms, and just see where the anxiety lies after that. But once the psychosis is treated, I mean, if you do have those residuals, anxiety symptoms or mood symptoms, then yes, they do need to be treated separately as well.

JO 51:48
What are other potential health complications associated with schizophrenia, and how do they affect longevity?

PHIL 51:56
Great question. Again, there are a number of other different health and we here we're talking about more medical health complications or comorbidities, that can happen with schizophrenia. And there's a number of factors that are associated with that too. And here, we kind of think more along the lines of cardiovascular health, for example, your cholesterol and lipids, about obesity, high blood pressure, diabetes, glucose intolerance as a result of that as well. And monitoring thyroid conditions too. And it's multifactorial, sometimes that could be a result of medications, particularly for the older medications in existence.

But other times it could be as a result of the illness itself. And perhaps some of the behaviors around the illness. And unfortunately, some of the situations too, and Katrina alluded to that as well, which having an illness sometimes leads people to find themselves in, such as in homeless conditions or situations where they're not able to, for example, have the healthy meals, activity, and exercise that they need to maintain cardiovascular health. These are the things that are monitored within the treatment teams.

JO 53:00
Thanks Phil, such important information. Taking a moment here to acknowledge our major HEADS UP sponsor, the Social Planning and Research Council of BC. SPARC is a trailblazer in Applied Social Research, social policy analysis, and community approaches to social justice. Thank you so much for your generous support.

Let's bring Kat and Chris back into the conversation. And we'll start by having you all bust the most common myths associated with schizophrenia. Myth number one, people with schizophrenia have multiple personalities.

PHIL 53:45

Well, that is indeed a myth. And I think it derives from the term schizophrenia as well, which people have misinterpreted as split or multiple personalities. But no, definitely, schizophrenia is not associated with multiple personalities.

JO 54:00
Myth number two, people with schizophrenia always hear voices. Kat, what's your experience with that?

KATRINA 54:08
That that's not true. It's actually a situation where not everybody who has mental illness hears voices and not everyone who hears voices has mental illness, there is a difference.

PHIL 54:20
I would agree with that Kat as well. So from an individual perspective, some people can have those auditory hallucinations, those hearing the voices. And then they go away. They can be episodic, but definitely not, an always kind of condition or state.

KATRINA 54:36
Yeah, I never actually heard voices. Lately, I hear music once in a while, but that's about it.

JO 54:42
Myth number three, people with schizophrenia are more violent or dangerous than other people, Chris.

CHRIS 54:49
Well, this is the most dominant, common, pervasive, and enduring myth around schizophrenia that the public in their opinion, they associate schizophrenia and bias together. And why is that? Well, the portrayal of people with psychosis and schizophrenia, if you look at media reporting, it historically has been very negative, focusing on violence and unfortunate criminal activity instead of addressing the complexity of schizophrenia, and high suicide rates, and media not telling us very much about the illness in general. Also, Hollywood movies, sitcoms, and even children's cartoons, how they have historically and currently do portray people in a negative way who have a mental illness, especially schizophrenia or psychosis.

The reality is that people with schizophrenia are more likely to harm themselves than others. When you look at the studies, approximately 97% of people with psychosis or schizophrenia are not violent. But for those people who are violent, and there is indeed a subgroup of people who will engage with the criminal justice system and act out a violent behavior, you have to look at the factors, all the factors that are involved in that happening. And even with a major Health Canada study, some years ago, talked about the multiple factors that are involved in a person engaging in violence, who has psychosis or schizophrenia.

And those factors are the following: they're not receiving effective treatment, they have a previous history of violence or a volatile behavior, they're engaging in misuse of alcohol or other street drugs, they are experiencing paranoid hallucinations and delusions, which triggers fear in the individual. It's not a simple answer, it's a complex answer, and we need to understand those multiple factors, that it's just not just the illness that's involved, when people act out and violence.

JO 56:43
Myth, people with schizophrenia require long-term hospitalization, Phil.

PHIL 56:49
That definitely is a myth. And I think one thing, though, we need to state out right, though, is that sometimes hospitalization is needed for various reasons. But again, it's a very individual thing. And I have people with lived experience in my practice, who have never been hospitalized, but they do have a diagnosis of schizophrenia. And I have other people that I see who, unfortunately, have had multiple admissions for various reasons. It's not an absolute, you don't require long-term hospitalization with schizophrenia.

JO 57:18
People with schizophrenia can't or won't work. Kat, you're living proof that this isn't true.

KATRINA 57:25
Yes, I love my job. And I love being the proof of that not being true.

PHIL 57:29
Yeah, that's great said Katrina. And from an outcomes perspective, and we're focused on getting people back to school, back to work, and people do want to get back to school and back to work. That really is the goal.

JO 57:42
People with schizophrenia are more likely to end up in jail, Chris.

CHRIS 57:47
Well, unfortunately, 3% of inmates in prisons are estimated to have schizophrenia or other psychotic disorders, like bipolar disorder. Approximately 16% of prison inmates have major depression. But really much of this is a result of failed mental health policy. And what I mean by that is the institutionalization that occurred in the 60s and 70s, the outdated treatment laws, demanding a person become violent before the intervention. All of that has driven those who are in need of care into to the criminal justice and corrections system.

So, we call that the criminalization of the mentally ill. And what they really need is to be in the public health care system where they can get help as opposed to being in a prison. That is certainly a social justice issue, for those of us who advocate for those who are living with schizophrenia and their family members.

JO 58:42
Another myth, schizophrenia is caused by bad parenting. Who wants to tackle that one?

KATRINA 58:49
I'll stand up for my mom. She was a good mom. My parents were excellent parents. It was other environmental triggers later in life of the traumas. And my mother had schizophrenia and schizoaffective by her final diagnosis point.

PHIL 59:07
Some of it comes back from some terminology, I think, which unfortunately, in this early early 20th century. I mean a term sometimes you hear more in history than anything else is a schizophrenogenic mother. But definitely we know that it's nothing to do with bad parenting.

JO 59:24

Chris, do you have a comment there, given that your mother suffered with mental health challenges, and many of your family members did as well? So, do you think that's genetics talking or the nature of your environment?

CHRIS 59:38
Well certainly mothers, I think especially feel a huge amount of guilt and shame. What is it that I did that caused my child to be born with schizophrenia? But no one is born with schizophrenia. It's something that you develop later on in life. And we know that it's not completely genetic, and that's been a great revolution of understanding since the time my brother was diagnosed with psychosis in the 60s.

Today, our understanding is that gene expression, how genes express themselves, it's very much influenced by environmental factors such as trauma. That can be in utero as well as a young child or in adolescence in terms of bullying. But even to this day, I think it's just one of those things, I don't want to call it natural, maybe that's the word natural, but mothers will especially feel guilt ridden. What did I do during the pregnancy? Or what did our home life have to do with it?

Let me say that, if you're in an unhealthy family dynamic, that's not going to be good for anything you experience in life in terms of your health care, whether it's physical or mental. So, addressing the family environment and the home is important in terms of its own mental health and resiliency, and wellness. But to say that a parent caused the schizophrenia is not based on any kind of fact, or scientific fact.

JO 1:01:11
Another common myth that people with schizophrenia will never recover, provides a perfect segueway into my next few questions, about the much-needed growing focus on recovery. In this case recovery, meaning people receive timely diagnoses, early intervention, and bio-psycho-social-vocational treatment strategies. A mouthful, I know, but we'll break it down for you after we first talk about recovery philosophy. Phil, how would you describe recovery philosophy from a psychiatric perspective? And how will that philosophy change to reflect emerging research?

PHIL 1:01:54
Recovery philosophy has been evolving over time. And as much as we understand and appreciate the illness of the individual, we evolve within the recovery philosophy. I've been working in early intervention services for quite a few years, and most of the services, our clinic here has been around for 25 years. And that is definitely part of the philosophy. So not necessarily new, but at the same time it's new enough, where we still need to be able to talk about it.

And really, the recovery philosophy is that appreciation that people with lived experience with psychosis, schizophrenia, can recover. And that's where we can look at then the definition of what, really what recovery is being a symptomatic recovery as well as functional recovery. And that sense of psychological well being, of course, as well. But a recovery philosophy is just more a construct in which we work within the medical system, that everybody has the potential to recover, how ever you define that.

JO 1:02:58
Chris, what does recovery philosophy mean to you as an advocate and recovery practitioner?

CHRIS 1:03:05
Well, we need to understand that recovery is not about a cure. And another thing is that illnesses don't recover, people do. And recovery as a concept, as a philosophy, and as a movement as it is today, has strong roots in the advocacy efforts of people with lived experience. So, we learn about the experience of recovery from the people themselves, who see it as a journey. They see it as a process, and indeed it is that. And even the Mental Health Commission of Canada, in 2006, in their landmark report and later other documents, said that recovery should be placed at the center of mental health reform.

Historically, the mental health system has been about symptom reduction. And that's fair, and that's understandable. But really, the goal of our mental health system should be that of quality of life, or life satisfaction. So, recovery is made possible by our providing safe places for people to be themselves. It's built on hope. It comes from a strength perspective as opposed to a deficit perspective. It's about shared decision making. That should be our goal. The goal of mental health services should be that of promoting quality of life and promoting recovery oriented mental health services. And we still have a long ways to go in that.

Recovery as a term is probably in all mental health documents and policies today. But it really hasn't filtered down into actual practice like it ought to be. Sometimes the contrast is between what some would call the medical model versus the recovery model. I think there can be an integration of both. It's an exciting field and it's at the heart of my advocacy, is that the mental health system in Canada is still sort of a mental illness system, as opposed to a mental health system. And if we move more to a recovery perspective, and see people rather than a diagnostic label, and learn and listen from patients and clients as to what helps and hinders their recovery, then I think we can see, as Dr. Tibbo talked about better outcomes in life satisfaction. Because you can be on all sorts of medication, and still not have quality of life.

So, recovery is about learning how to live beyond the limitations of a mental illness, with a sense of purpose, and hope, and meaning, and social inclusion. If you don't have that hope, if you don't have that meaning, if you don't have social inclusion and full citizenship, you can live a pretty sad, unfortunate life. Because there's no such medication that can give self-identity, affordable, safe, adequate housing, that can give you a job, and there's no medication that can give you the privilege of full citizenship and social inclusion.

JO 1:06:11
Kat, what do you hear from your peers about recovery? And how do you balance their expectations with realistic outcomes?

KATRINA 1:06:22
We want our lives back. That's what it comes down to. We want our lives back; we want to be able to live our lives and live liked. We want that, that everybody else has, that somebody with diabetes still has, even though they have diabetes. In my area for where I'm focused it's not exactly a direct conversation piece. But it comes out that without the life, to be able to be living with social determinants of health, being out of order and out of alignment, it sucks. And that's what we want to get toward is a betterment there.

Because what does ongoing recovery mean and look like? It means still continuing forward, even when there's still steps or setbacks. It means finding strengths and using myself determination, it means being able to be a full person. It means continuous learning, and growth, and development. It means being able to move forward with desires, goals, and hopes. I'm hoping to be able to, as a peer support worker, help relate that in people.

JO 1:07:46
So in short, your future looks bright.

KATRINA 1:07:49
That is what I'm hoping, yes.

JO 1:07:51
How do you all feel about the language we use around recovery? Are there some definite do's and don'ts we should know about?

CHRIS 1:08:00
Family members often have difficulty with the word recovery, because they feel that that implies that the person recovers back to what their child once was, and they don't. I actually like the term recovery because we all, through our life journey, are recovering from so many different aspects. Currently, we're recovering from COVID. We all are recovering, and will be recovering from different things in life, whether that's positive or negative. It helps us to become the person we are.

When parents ask me questions like well, will my son get better? Will my daughter be able to function again? Will they have a life? And really what they're saying is, will the person be able to recover from this trauma, from this mental illness, from the deficits, from the losses? Yes, I believe that people can if we provide them the right kind of recovery environments for that to take place.

PHIL 1:08:58
I fully agree with you Chris as well on all those points. And I think, just to add in here, like when I'm speaking to and working with various clinicians at all levels, I also emphasize what recovery is but also, I think you alluded to this earlier Chris as well, that we just don't focus on what I call symptomatic recovery. Fortunately, if you just focus on symptomatic recovery, there still is that potential to miss what is still needed to get that person to recovery that they feel is important.

JO 1:09:31
Here's the $64 billion question. What do you all think it will take to move us from understanding and appreciating recovery theory, to embracing a recovery movement supported by government policies, programs, and funding?

CHRIS 1:09:47
I think at the heart of any transformation, it has to be the patient. We know that in other dimensions of health care, but we've been slow coming to that in psychiatry and mental health services. So, learning from the patients and clients fundamentally, as the question I alluded to earlier, and that is what you believe will help you, what you believe hinders you in your recovery process. And so meaningful engagement of individuals as well as family members, they're the ones who live with us. They're the ones who live with the consequences and the fallout associated.

They may not use the word social determinants of health, but they know about the extreme losses that can be associated with mental illness in terms of getting a job, finding affordable, decent housing, dealing with stigma, which we'll probably address later on. And so, it's important while we value the knowledge, and expertise, and skills of professionals and mental health service providers, that we come back to that old mantra that a number of organizations use, and that is nothing about us without us, and that that be meaningful and not tokenism.

PHIL 1:11:03
And the only thing that I perhaps like to add to that which are all important points, of course, is for us to move from theory to embracing. We still need a lot of education and advocacy to happen around recovery, what it is and what it can entail. And that's education, not only to individuals and family, but as well to the broader medical community and, of course, to the general public. Part of this whole podcast is about education that will help these types of activities, help us have that feel of embracing what we really want recovery is, and as well that advocacy piece towards government, for allowing us to have the resources to fully embrace recovery.

JO 1:11:43
We're near the finish line of part one of our podcast on schizophrenia. My last question focuses on the first two pieces of the recovery puzzle. We'll explore the other pieces in Part 2. Phil, timely diagnosis and early intervention are important first steps in the recovery process. Why are they so important? And how should they unfold?

PHIL 1:12:07
The earlier a diagnosis is made and if it was timely interventions, the better the outcome. And really that's our goal. So, this led to the development of early intervention services, which to say most of our programs in Canada now have been operational for quite some time. Our program here in Halifax has had its 25th anniversary, and as well it was one of the first three programs in Canada to be developed. And importantly, research has been in step with early intervention services, and understanding the illness and research even into service delivery as well. It is a bit of a philosophy.

But it's also important to realize the research has definitely shown that if you diagnose early, and the proper treatment is there, then the better the outcomes. That goes perhaps against some of the historical ideation of schizophrenia, which tend to be a bit more nihilistic. Some people have difficulty even today, understanding that a significant majority of our population that we see in our early intervention program, will be well enough that once they leave our programs, they'll just need to follow up with a family physician. Now that said, I mentioned earlier that the illness can affect people differently. And some people, much like diabetes, need a bit more care as well. But that's the importance around early intervention really is allowing us to optimize those outcomes.

JO 1:13:27
Kat, could your diagnosis have unfolded better?

KATRINA 1:13:31
Yes, I believe it could have. Part of it was my own self-inflicted doing, by the not realizing, recognizing, or acknowledging when people approached and did say something was wrong. But all I saw was the stigma. I actually saw that as the biggest thing, and I didn't see how it fit.

JO 1:13:54
Phil is it common for people in the early stages of diagnoses, to fail to see what's actually there?

PHIL 1:14:01

Yeah, it's not uncommon. Part of the illness itself revolves around insight, and insight and knowing that your experiences that you're having are not normal experiences. If we're there early enough where there's the people at least be able to appreciate okay, something's not quite right. I need to get help for it. But if insight's an issue that's when you have to rely on family members, or from family physicians, or other gatekeepers of the community.

JO 1:14:30
Kat, can you share some of the frustrations felt by your peers as they navigate their diagnoses through the healthcare system?

KATRINA 1:14:39
It ranges depending on the pure frustration, but some of the commonalities are wait times, wait times before the referral for the psychiatrist, or the ability to get a psychiatrist when they need one, want one. Bouncing around in the system of it. I've heard a few instances, well this doctor said this thing, this doctor said the other thing. Which one am I supposed to listen to? It just depends on the peer.

JO 1:15:06
Chris, you talked about early diagnosis and how it could have changed your brother's mental health outcomes. What would that have meant to your family and his broader community?

CHRIS 1:15:19
Well, if my brother had received what people ought to be receiving today and we can give them, there would have definitely been less agony and suffering within the Summerville family, less hopelessness. Early intervention may well have prevented him from developing full-blown schizophrenia. There would have been less profound losses and less burden to the family.

Recovery oriented services would have provided him with peer support. And the value of peer support is the mutual lived experience. Two people being able to share emotionally in a supportive way, their experience with mental illness, and then the possibility and experience of recovery. The value of peer support, that contact-based education as we call it, I think in terms of all the trauma that we experienced as a family, there would have been less of that if there had been what we call today, trauma informed care, as well as addressing the social determinants of health and addiction issues. We would have had less hell in the family, it was hell on earth.

It wasn't just the cause of the schizophrenia. It was about a society that did not know how to respond to a family that was not educated or knew how to respond. Our knowledge of schizophrenia and recovery, it's been profound, it's been tremendously significant. Our understanding of psychosis and schizophrenia has grown in the six decades since my brother developed psychosis. I mean basically in the 60s, I never heard the phrase, once I heard the phrase, kiss of death diagnosis. That's actually what we were experiencing as a family, for those in my family who were struggling with mental illness.

It doesn't have to be that way. And it doesn't have to be that way for people today, because as Dr. Tibbo was talking about the importance of education, and that education is a holistic one. Because the response to schizophrenia is not just biological. You have to address the psychological, the social, the communal, in terms of how communities respond to it. And there's also a spiritual element in it. You're looking at the whole person. And yet it may not and should not be an individual journey or just a family journey. For recovery to happen, it takes the support of a caring community.

JO 1:17:41
Kat, Chris, and Phil, thank you so much for helping to build these needed communities. Your stories today, your ongoing passion, and your work that informs and inspires recovery practices are truly transformative.

That's a wrap on Part 1 of our podcast about schizophrenia. In Part 2, we'll explore the role of stigma, and dig into more recovery strategies such as proven bio-psycho-social- vocational supports, a mouthful for sure, emerging science, and advancing technology. You won't want to miss it.

To connect with Kat, Chris, and Phil find the episode show notes on our website. You'll find their detailed contact information, complete bios, and a transcript of the episode. Thanks to all of you listeners as well for hanging out with us until the end, much appreciated.

If you haven't done so already, please visit freshoutlookfoundation.org and sign up for our regular E-newsletter, which will alert you to new episodes of the podcast and our virtual summit. And for ongoing information, follow us on Facebook at FreshOutlookFoundation and Twitter at FreshOutlook.

In closing, as Winnie the Pooh says, I'm lucky to have something that makes saying goodbye so hard. Instead, I'll say be healthy, and let's connect again soon.