Lisa Dixon (00:07):

Welcome to our podcast, Psychiatric Services From Pages to Practice. In this podcast, we highlight new research or columns published this month in the journal, Psychiatric Services. I'm Lisa Dixon, Editor of Psychiatric Services, and I'm here with podcast Editor and my co-host, Josh Berezin. Hi, Josh.

Josh Berezin (00:26):

Hi, Lisa.

Lisa Dixon (00:27):

Today, we're going to talk about an article from the journal that was recently published online, Shalini Lal and colleagues wrote on the issue and perspectives of relapse among individuals experiencing first episode psychosis. I'm really looking forward to it.

Josh Berezin (00:45):

We're very fortunate to have Dr. Shalini Lal, who is the Canada Research Chair in Innovation and Technology for Youth Mental Health Services and an Associate Professor in the School of Rehabilitation, Faculty of Medicine, University of Montreal, here with us to talk about her and her co-author's paper, "Young Adults' Perspectives on Factors Related to Relapse After First-Episode Psychosis: Qualitative Focus Group Study." Dr. Lal, thank you so much for joining us.

Dr. Shalini Lal (01:10):

And thank you. It's a pleasure to meet both of you, and thank you so much for this opportunity to chat about this study.

Josh Berezin (01:16):

We always start off with a question about how you found your way into this particular area of research and how it kind of fits in with your broader interests and research projects.

Dr. Shalini Lal (01:26):

Yeah. As a researcher, I've spent a good part of my PhD, my postdoc, and my early career focused on research pertaining to the well-being of young people that have experienced first episode of psychosis, and I came to that population context by my way of clinical background. I'm an occupational therapist by background, and as a young OT, about 20 years ago, I had the wonderful opportunity to work at the Allan Memorial Institute. For those listeners who are not familiar, the Allan Memorial is affiliated with McGill University, and it's located in downtown Montreal, Canada. It was to work in one of the first early psychosis intervention clinics in Canada at that time. I call it a startup clinic because at the time, there was like a part-time psychiatrist, part-time psychiatric nurse, and they got philanthropic funds to hire a part-time OT to address the psychosocial needs that they were observing in the clientele.

Lisa Dixon (02:28):

I just have to say I am so happy that we have an occupational therapist on our podcast.

Josh Berezin (02:36):

You're our first.

Lisa Dixon (02:37):

You guys are so important, and it's just, makes me happy.

Dr. Shalini Lal (02:42):

Thank you so much. I really appreciate that feedback and this opportunity. Providing services to young people with the first episode psychosis, I think requires a community, and I enjoy very much working with psychiatrists. I've worked with psychiatrists for a long time, as well as many other people from different types of disciplinary backgrounds. I was so inspired by that first experience working in the Early Psychosis Intervention Clinic, that a few years later, I transitioned to the role of case manager, and eventually clinical program coordinator of a specialized early intervention program for first episode psychosis at the Douglas Mental Health University Institute in Montreal.

(03:22):

As you may know, the main mission of these programs is to support the psychosocial recovery of young people that have experienced a first episode of psychosis, and relapse can pose a major challenge and obstacle in achieving that mission, so as a case manager, I witnessed firsthand how relapse can derail young people's efforts under buying patient, family, hope, and optimism, and for clinicians, it can be disconcerting as well, especially when a relapse results in a hospitalization, or even worse, outcomes than that, and so when the opportunity to work on this study came about, I was really, really keen because the clinical implications and the value for engaging young people in a conversation around relapse were so clear to me, but I was also a bit trepidacious because I wasn't sure how participants were going to react to the topic. I wasn't sure if we were going to end up recruiting a whole bunch of patients into a room, and then relapse became the elephant in the room that nobody was going to be comfortable to talk about.

Lisa Dixon (04:33):

I think a lot of us and a lot of our listeners are going to relate to this notion of, "Where did this word come from, relapse?" I find myself wondering whether it should be banned from the dictionary. Anyway, that's one of my favorite things about this paper, is that it really shines a light on this word. I'm respectful of the fact that you knew that.

Dr. Shalini Lal (04:57):

Yeah, and a lot of my previous research before that study was focused on concepts like recovery. My PhD was focused on concepts like resilience, and then now, this was a bit the antithesis of that or the complete opposite of a, "No, we're not going to talk about post-traumatic growth, we're not going to talk about resilience. We're talking about relapse," so I really was not sure and how people were going to respond to this, but as we can see from the results, patients, participants had a lot to say about it. In the paper, it's distilled into 4,000 or so words, but there were these long transcripts and the focus groups lasted over an hour, some of them, so there's a lot of content. It was quite a bit of a challenge to distill all that into what we see in this paper.

Josh Berezin (05:48):

Okay. We're going to get to the paper very, very soon, but we're not going to be able to do this question justice, but could you tell me and our listeners, is there an OT perspective on first episode psychosis that would be distinguishable from a psychiatric perspective? What is your training and background as an OT? How do you look at clients, and how do you look at the field differently than I might from my psychiatric background?

Dr. Shalini Lal (06:21):

That's a very good question. Occupational therapists focus a lot on the activities that people engage in and how those activities can contribute to their well-being. They're very much interested in activities that are considered valuable or valued by patients. We might sometimes think work. Work is really important and we need to support everybody to get back to work, but for any other individual, it might not necessarily be work.

(06:50):

It might be, "I want to engage in my music," or, "I want to be able to provide care for my child." It may be different things, and so we're very much interested in first, understanding, "What are the activities that are valued by a person?," and then helping them in terms of achieving those activities, because we understand that those activities can contribute to well-being in very different types of ways. It can contribute to well-being in terms of creating meaning, it can contribute to well-being in terms of facilitating connection to others, it can contribute to well-being in terms of cultivating strengths of an individual. I would say that that's kind of probably one angle or a way that we might approach recovery differently than sort of the biomedical type of an approach.

Josh Berezin (07:36):

Before we get too derailed on this topic, because we could definitely talk for 45 minutes about occupational therapy, like I'm very interested in the perspective that it's bringing, but we should probably talk a little bit about the paper, so tell us a little bit about the study. Who were you talking to and what sorts of questions were you asking in these focus groups?

Dr. Shalini Lal (07:55):

I'll start off with just talking a little bit about relapse since that was the focus of the paper. I'll start with defining relapse and how it's operationalized in the literature before I say more about what we know about the rates of relapse. It's important to note that this is really not actually as straightforward as one might like it to be, so researchers that have conducted literature reviews and systematic reviews on the studies that are trying to understand what are the relapse rates in early psychosis have been faced with a lot of methodological challenges in determining what are the relapse rates. Some examples of these methodological challenges ... I won't go through all of them.

(08:35):

I'm sure there are many even that I'm not aware of. Relapse first is defined inconsistently across studies. The criteria for determining if a person has had a relapse is also inconsistent, including the duration of relapse and the extent of remission following the relapse, and so forth. Nonetheless, researchers will define relapse, generally speaking, as a worsening of positive symptoms such as hallucinations or delusions, or they'll use hospitalization rates as a proxy for relapse rates, and sometimes researchers will look at both pictures.

Lisa Dixon (09:10):

I'm getting really eager to hear what people have to say. I mean, I find this sometimes to be so depressing. I think that what you've been describing is kind of this very traditional, symptom-oriented, almost binary that is just not ... We just know it's not helpful. I mean, I'm someone who ...

(09:34):

I work in this space, and I've lived this space with my brother. All these data on relapse rates and hospitalizations, I mean, it's all important and we need to kind of understand what helps people, but at

the end of the day, what I think is so cool about this study is it just kind of shines a very different light in a way that's much more hopeful and gives ideas for how to move beyond this sort of relapse binary.

Josh Berezin (10:05):

Let's maybe get into the study. Who were you talking to? What questions were you asking? What were you doing?

Dr. Shalini Lal (10:10):

I was just going to say, just to respond to Lisa's comments about it, and as you say, more hopeful, and I think also, straightforward in many ways because the factors are modifiable. They really do tend to give us an indication of, "What can service providers be thinking about and doing to help support recovery essentially and prevent relapses along the way?" Essentially, the study was part of a larger qualitative study on patient and family experiences on the perspectives of relapse and its prevention. We had previously published our findings from the family groups, and this is a paper we focus on the patients. Who are we talking to?

(10:50):

We recruited patients from four early intervention services for psychosis in Canada. They were all young adults, the average age was 24, the majority were males, and the average length of time that they spent in the early intervention program at the time of recruitment was a little more than two years. About 40% had expressed that they had a history of relapse with the rest either not being specific about their relapse history or they were uncertain about whether or not some of the experiences that they had in the past would constitute a relapse, so this was a big challenge for us in terms of trying to provide a picture for the reader in terms of how many of these people had had a relapse or not.

Lisa Dixon (11:34):

I mean, that says so much about it. I don't know if I had a relapse or not because you're not speaking my language.

Dr. Shalini Lal (11:40):

Exactly. Exactly, and so we conducted essentially four focus groups. The focus groups lasted between 60 to 90 minutes each. I was the main facilitator of these groups, and there were three members of our research team that were involved in the analysis process. In terms of the discussion, like what did these focus groups consist of, the discussion covered topics such as conceptualization of relapse, impact of relapse, how participants recognize relapse, and the factors that they perceive can contribute to and prevent relapse.

(12:17):

In this paper, we're really focusing on that last piece that I just mentioned, and we did that through two sets of questions. The first was, "What comes to mind when you hear the word relapse? How would you define it?," and the second set of questions were, "Well, what helps to prevent a relapse from happening, and what's not so helpful in preventing relapse?"

Josh Berezin (12:38):

So how did you categorize things and summarize some of this information from the many, many hours of transcripts?

Dr. Shalini Lal (12:44):

I guess I'll start by first saying that if a factor was mentioned by at least four of the participants out of the 25, then it was listed or included in our list of factors, and we categorize factors in terms of what contributed to relapse and what the participants perceived as prevented relapse, and in terms of the factors that participants perceived to contribute to relapse in descending order of frequency, they identified substance use, unsupported or unsupportive social environment using technology, taking and not taking medication, lack of sleep, stress related to work or career or school, significant life events, and that could have been positive or negative life events, symptoms of depression or mania, generalized worry, and financial stress. In terms of the preventive factors in descending order frequency, and you'll hear some of them a bit repeated in a different way, they identified having a supportive environment or supportive social environment using technology, taking medication, using coping strategies, and engaging in healthy lifestyle behaviors and meaningful activities as factors that can help to prevent relapse.

Josh Berezin (14:04):

What stood out for you when you were hearing these things or when you were categorizing them? How do you think about what was novel? What maybe surprised you? Was there anything or a way that you kind of conceptualize the results in general?

Dr. Shalini Lal (14:20):

What's interesting about all of these factors is that four of them were discussed in terms of both their contributory and preventive roles. They talked about the social environment as how it can support preventing relapse and how it can actually contribute to the relapse. They talked about the use of technology in terms of how it can prevent or contribute to relapse. They talked about medication in terms of how it can prevent or contribute to relapse, and they talked about lifestyle behaviors in terms of how that can contribute or prevent relapse. I thought that that was interesting that there are these two sides of the coin for those four factors for these participants, and that they saw two sides of the coin.

Lisa Dixon (15:01):

Yeah. I thought, in particular, the use of technology was very interesting and very informative how it could go both ways.

Dr. Shalini Lal (15:10):

Yeah, and that was very interesting for me too, because a big part of my research is focused on the use of technology to increase access and quality of services in specialized early intervention care, so hearing about how technology can actually contribute to relapse from these participants was important for me because I'm on the side of using technology to try to get participants to access different types of evidence-based services and supports.

Lisa Dixon (15:39):

In that vein, just sort following up on the technology piece, what did you learn that you didn't know before, or what are some takeaways around the helpful use of technology and avoiding the toxicity of it?

Dr. Shalini Lal (15:53):

Yeah, so participants talked a lot about how technology can be helpful. They gave examples, such as it can help them to stay connected with family and friends. It can help them to access explanations about the psychosis and the experiences that they've been going through. It can help them access different types of information related to the medications that they're taking, and things like that. At the same time, they talked about how, if you've gone through a psychosis, then you can be vulnerable when using technology in the sense that it can potentially trigger thoughts like you're being monitored or being tracked and things like that. That's interesting for researcher like me, who's been looking at the potential of using technology perhaps to help with symptom monitoring with this population.

Lisa Dixon (16:45):

Yes, you are being tracked.

Dr. Shalini Lal (16:47):

Exactly. Exactly.

Lisa Dixon (16:51):

It seems entirely understandable to me that it would have this dual effect.

Dr. Shalini Lal (16:55):

Yeah.

Lisa Dixon (16:56):

Maybe just being able to talk about it is part of what is a lesson here.

Josh Berezin (17:01):

It also seems like it complicates interventions, so I'm thinking about I go online to get some information that's going to be helpful to me and my health, or my education or something like that, and then five minutes later, I'm on some Twitter black hole, that I'm just totally, I did not mean to do that, and so it's like if something can be both helpful and harmful, you can't ... It's like increasing access to the internet is not going to be your solution here, because it has pros and cons, and so how do you design something that's a little more nuanced that's going to bring out some of the positives without bringing up some of the negative potential effects?

Dr. Shalini Lal (17:42):

Yeah. In my previous research on this topic, so I did a study a while back where we really looked at whether young people with first episodes of psychosis do go online to search for information, how do they go online, where do they go when they're looking for mental health related information, and we found similar experiences as you were describing, where they're challenged to know where to go, first of all, that across the participants they search for information in all kinds of different ways. Some will go to WebMD, some will go to do a Google search, some will go to Yahoo.com, et cetera, et cetera. They have this sentiments of questioning the validity and reliability on information, but at the same time, those participants didn't have any other alternative, like they were not hearing necessarily from service providers as to where they should go to get information, so that tells us that the topic of the use of technology to access mental health information, peer support, testimonials, and things like that is an important topic for service providers to have with patients, and maybe service providers also need to

have an increased capacity for how to recommend or how to go about even having those discussions, and what and where to recommend for patients to go, and perhaps the need for specialized early intervention programs to have a bit more of a standardized place or tools that patients can access this type of information in a reliable and safe way, and different types of information because it's not just sort of like, "What is psychosis? What other early warning signs?," but hearing about testimonials from others is an important aspect as well to have access to.

Josh Berezin (19:20):

The other kind of category that could be both protective and contributory that really stood out to me was social environment. I thought that was really interesting as well in a similar way to technology, so I was wondering if that was also something that piqued your interest, and if so, what you kind of took from that.

Dr. Shalini Lal (19:37):

Yeah, it definitely piqued my interest. It resonated with some of my previous research in terms of what supports recovery, what supports resilience. The social environment tends to keep coming up in different ways across the studies I've done. In this particular study, what was interesting is that participants provided some different types of examples of what constitutes an unsupportive behavior from the social environment and what constitutes a supportive behavior. For example, with respect to an unsupportive behavior, they talked about how, when family members were perceived as being judgemental, when participants were being told what to say or do by their family members, told how to think, or family members expressed a bit of impatience with the process of recovery, even when they were constantly checking in or inquiring about their well-being, or expressing their own stress. These were perceived and experienced as factors that could contribute to their own relapse.

(20:37):

Examples of unsupportive behaviors from healthcare providers typically revolved around information and explanations regarding symptoms and treatment. For example, one participant said, "The least helpful thing for me would be the nurses and doctors insisting, that everything bad that has happened to me is delusion, just like it's over and over, and it's really hurtful." On the flip side, they also talked about supportive behaviors from the social environment, such as being trustworthy, listening, having patience, expressing genuine concern, and in relation to healthcare providers, they specify that being understood and validated, being given clear information regarding illness, symptoms, treatments, and having timely access to appointments were examples of the types of behaviors that were perceived as helpful for preventing relapse.

Josh Berezin (21:27):

For me, obviously, the healthcare provider section stood out, and it was just a reminder that the way you comport yourself, the words that you use, your emotional tone, they really matter.

Dr. Shalini Lal (21:43):

Exactly, and that's essentially what our participants are saying. I think it comes down to, as well, that therapeutic rapport, therapeutic relationship, and how important the therapeutic relationship is in recovery. We know that as well from a previous research.

Lisa Dixon (21:57):

Can you share just a little bit about how people understood the word, relapse? What does that mean? Obviously, there's not one single truth here, but what did you take away from the discussion about what relapse means?

Dr. Shalini Lal (22:12):

The key thing that stood out from when we asked participants about, "What comes to mind when you hear the word relapse?," "How would you define relapse?," is that there was a lot of uncertainty about how to define it across the participants, to the point that some of the participants even return the question back to me, asking me, "So you tell us. You tell us what. What is relapse?"

Lisa Dixon (22:33):

Good answer.

Dr. Shalini Lal (22:35):

Yeah, exactly. Another participant said something like, "I still haven't had a clear definition," so I think that actually captures and says a lot. Unpacking this further, we came to understand that their uncertainty was often related to, "Which symptoms and behavior needed to be present to constitute a relapse?" For example, is it just symptoms of psychosis, or what if a person had a change, increase in the symptoms of depression, but they had history of psychosis, and now they're just having symptoms of depression? Does that constitute a relapse?""How severe do the symptoms need to be? How long do they need to persist to constitute relapse?" To illustrate that, one participant said, "I've had instances where it'll come back, but it might only be for a few hours, so is that considered a relapse? I'm still a little iffy on the definition." Another participant said, "I heard loud voices and became extremely paranoid about them, but then, I slept it off and it went away, so I'm not sure if that's a relapse."

Lisa Dixon (23:38):

So it's like they were trying to jam their own notion to our definition, the system's definition.

Dr. Shalini Lal (23:48):

Yeah.

Lisa Dixon (23:49):

And instead of, perhaps, what we really want is to understand their experience and what is painful for them or difficult for them and what is helpful. Yeah, there's just a lot here to think about.

Dr. Shalini Lal (24:03):

Yeah, that's true. I would say that it seemed to me that in many ways, they were aligned with the system's definition and what we have in the research literature, and probably what they have heard from service providers, and in other ways, they tended to expand. They had other perspectives or other ways of approaching this concept of relapse. In general, it felt like they essentially had a broad definition of relapse. They tended to define it in terms of some kind of a change.

(24:32):

It could be a change in terms of symptoms, but not necessarily only psychosis-related symptoms, anxiety. It could be a change in relation to anxiety, for example, from their perspective, changes in thoughts, behaviors, functioning, physical state. Like maybe having a lot of energy is an example that

one of the participants gave, and so there tends to be a bit more of a broader, I would say, approach or perspective, and possibly also because maybe there hasn't really been any specific, clear definition for that.

Josh Berezin (25:04):

I mean, when I read their responses in the paper, I was like, "That is a good question." You know? I was like, "That's a great question to ask. Is that a relapse? Does it matter if we're calling that a relapse or not calling it a relapse?"

(25:19):

Like to Lisa's point earlier, I thought their answers were sort of provocative in terms of like, "Is what we're doing matching people's experience?," and the answer seems to be no.

Lisa Dixon (25:32):

Or perhaps sometimes, right?

Josh Berezin (25:34):

Yeah.

Dr. Shalini Lal (25:35):

Yes.

Lisa Dixon (25:35):

That part of the paper and this discussion also reminds me of sort of the value of doing qualitative research, because it really provides space to have that conversation as opposed to, "What's your answer? Check the important, not important, used to be important," because you could easily, in some ways, make like a questionnaire, or you can use a questionnaire, which I'm not against questionnaires. I don't want anybody to think I'm against questionnaire, but-

Josh Berezin (26:06):

All you questionnaire enthusiasts out there, do not worry. You are simply [crosstalk 00:26:11]-

Lisa Dixon (26:11):

Right, right, but I find myself thinking, "What would we have learned had you not approached this question using these qualitative methods, if you had tried to instead used more of a closed-ended quantitative approach?"

Dr. Shalini Lal (26:27):

Based on what I mentioned before earlier on, when we started our conversation about the methodological issues in terms of operationalizing relapse, we can start to understand that relapse is a complex phenomenon to understand, especially when we're wanting to investigate how patients understand this concept, what does the process of relapse entail, what factors can contribute to and prevent relapse, focus groups are a great method for unpacking complex phenomena like relapse. Given that relapse is also a sensitive topic, the group context relieves some of the pressure to answer all the questions from a researcher at any given time. It provides participants with more space and opportunity

to reflect on the topic in comparison to a one-to-one individual interview scenario. The power dynamics between a researcher and a participant can also be minimized in a focus group setting because there's the collectivity or the collective group of the participants, so the idea of together, we are stronger, so we felt that this may help to empower participants to share their perspectives on this topic, and so these are some of the reasons why we felt that focus groups as an approach would be a good way to engage participants in this study. I was going to go back to also just saying something earlier.

(27:45):

We were talking about the questionnaires versus the qualitative. I had, as a clinician way back when, I had a similar experience when I first started working in the early psychosis field. As a clinician, I was a recipient of a lot of the results of research that was emerging in this field, and I remember sitting in the room ... This was before doing my PhD and becoming a researcher. I remember sitting in the room and saying, "Oh, well, that's great that patients are satisfied with this and that on a scale of one to five," or, "That's great that we've had this outcome or that outcome," but what do the participants say about that?

(28:21):

Where are the voices of the participants, or where are the voices of the patients in all of that? What about the family members, and what do the clinicians think about that? There was always this kind of yearning from me to hear more the stories and the perspectives, and this was a great opportunity to really sit down and have that conversation with patients on this very, very important topic.

Josh Berezin (28:48):

Well, that's probably a good place to wrap up, but before we do, I'm interested in hearing what you're working on now.

Dr. Shalini Lal (28:52):

What I'm working on now is a couple of different projects, but mainly focus on the use of technology to improve access and quality of mental health services to this clientele, and it links up with some of the results in the sense that participants talked about how, for example, lifestyle behaviors and having healthy lifestyle behaviors is important, so that tells us that it's important to provide access to these, and technology can be a very good way to do that, and so one of the platforms I'm studying is a platform called MOST. It was originally developed in Australia, and it's a platform that provides that opportunity for patients to have access to peer support, as well as different type of content related to promoting good, healthy lifestyle behaviors like sleep hygiene, as participants in this study talked a lot about how sleep and not sleeping well can contribute to a relapse, and so in this platform, we can have evidence-based information on having good sleep behavior. That's an example of how the work that I'm doing currently connects with the results from this study.

Josh Berezin (30:01):

Well, we'll have you back on when we hear what the results of your current work is, but thank you so much for the paper, and also for joining us, for being our inaugural occupational therapist. It was a great conversation. It's a fantastic paper, and we hope everyone will read it.

Dr. Shalini Lal (30:18):

Thank you so much for this opportunity. I'm really honored to be your inaugural occupational therapist, and I hope that you'll have more coming to your podcast in the future. It's been a great opportunity. I appreciate the platform to share the results of this study, and I wish you both well.

Lisa Dixon (30:34):

Thanks much. Appreciate it. We invite you to visit our website, ps.psychiatryonline.org to read the article we discussed in this episode, as well as other great research. Also, check out Editor's Choice Topic Collections available now. We welcome your feedback.

(30:51):

Please email us at psjournal@psych.org. I'm Lisa Dixon.

Josh Berezin (30:55):

I'm Josh Berezin.

Lisa Dixon (30:56):

See you next time.

Speaker 4 (30:57):

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