Psychiatric Services From Pages to Practice – Dr. Mette Ødegaard Nielsen – November 2024

Dr. Lisa Dixon (00:07):

Welcome to our podcast, Psychiatric Services From Pages to Practice. In this podcast, we highlight new research for 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.

Dr. Josh Berezin (00:26):

Hi, Lisa.

Dr. Lisa Dixon (00:27):

Today, we are going to talk about an article that describes a service in Denmark that focuses on tapering of antipsychotic medications.

Dr. Josh Berezin (00:37):

We're very happy to have Dr. Mette Ødegaard Nielsen here to talk to us about her paper, Motivations for Experiences with Antipsychotic Tapering Among Patients with Schizophrenia Seeking Guided Dose Reduction. Dr. Nielsen is a senior research and associate professor at University Hospital of Copenhagen. Dr. Nielsen, thanks so much for joining us and for the brief lesson in Danish before we started recording.

Dr. Mette Ødegaard Nielsen (01:02):

It's a pleasure.

Dr. Josh Berezin (01:04):

So tell us a little bit about your background and how you came to this particular topic.

Dr. Mette Ødegaard Nielsen (01:08):

Well, I've been a medical doctor for 20 years and in psychiatry most of the time. And after my PhD, in my postdoc, I did some re-examination of the cohort that I have seen in my PhD. And what I saw there was that these patients who have had schizophrenia diagnosis for between four and eight years, they had really different outcome. So some of the patients were without medication and doing really well without any symptoms anymore, and others were more chronified, and despite that they had medication.

(01:44):

Then in 2017, the Danish government had this idea that they should make this clinic where people could get tapered. And my professor, Jimmy Nielsen assigned for doing this work and got some money to start this clinic, and then he started collecting data and I was associated with the project as well. And then when the project finished, we looked into the data together. And we are now still running the clinic but have expanded the period for tapering and still doing some research on this topic.

Dr. Josh Berezin (02:22):

So why did the Danish government open a clinic specifically geared towards tapering medication? What was the context for the government involvement? And maybe that is also a little bit of a segue to talk a little bit about how people with serious mental illness receive health services in Denmark maybe tied together, but maybe they aren't.

Dr. Mette Ødegaard Nielsen (02:44):

Yeah. Well, in Denmark all health services, almost all health services public. Outpatient clinics are mainly for patients with severe mental illness and also hospitals. And they are all governmental finance. They are private practitioners or specialized psychiatrists, but they're also governmental finance. So you don't have... Well, there is health insurance, but you don't need to have it to get care. And then there are several strong user organizations both for patients in psychiatry and also their parents and sisters and relatives and these organizations had for several years made this pressure that they wanted medication-free treatment like it has been done a few places in Norway.

(03:33):

And that was actually the start scope for the clinic. However, there were no Danish psychiatrists that wanted to sign into... That it had to necessarily be medication-free. So it was a kind of compromise that it should be aiming at tapering down medication. Maybe people could be medication-free, but that was not the main idea of the clinic. The main idea was to help people to taper down medication. So that was why it was funded by the government back in 2017 and then the clinic started in 2018.

Dr. Josh Berezin (04:09):

Well, in your discussion section of the paper, you also talk a little bit about some of the controversies around tapering. I think both just in the field of psychiatry in general and in Denmark in particular. And I thought before we dive into a little bit about the details about the paper, you could lay out some of what that controversy is around medication tapering.

Dr. Mette Ødegaard Nielsen (04:30):

Well, I think that the controversy is that we know that at least some patients, and then the discussion is how many patients will get a relapse of even psychotic symptoms when they taper down their medication. So for some patients with schizophrenia or other chronic psychotic diagnosis, we know from a lot of studies that going out of medication will result in a psychotic relapse.

(04:58):

And because of this, there are a lot of psychiatrists and professors saying that it's almost unethical to taper patients down medication because you can expect a relapse. However, if you look at all these papers, even when Bleuler and Kraepelin were active, they also mentioned that you have a subgroup of patients that actually recover from psychotic symptoms completely without medications. And the degree is discussed, but in most studies it's like two out of 10 that do not have a relapse within the first three years.

(05:38):

That's the long studies. Even though they do not take any medication. And the problem is of course then there may have a relapse and a severe relapse because sometimes a relapse where even if you start up medication again, you cannot be able to treat the symptoms as well as you could before. So that's discussion why some doctors say that it is almost unethical to try to taper. However, we also know that almost all patients at some point wish to try to do without medications because they have a lot of... That's also what the paper is about. They have the side effects, but also this idea that the circumstances, their life circumstances have changed.

(06:20):

They have learned to deal with some of the symptoms in a way that they do not dig into a terrible psychotic face, but can handle some of the symptoms and have a nice life even though they have a little

symptoms. And then that's why almost all patients want to have at some point tried to skip medication. And our argument is that if you don't help patients giving them medication, they will do it on their own. And when they do it on their own, they often skip it very quickly and that's for sure makes the risk for developing a lot of symptoms, withdrawal symptoms, psychotic rebound symptoms even higher. So the risk is higher for developing these symptoms if they stop suddenly or pretty rapidly.

Dr. Lisa Dixon (07:07):

Well, I wanted to just jump in for a second and share a personal experience, which was during the pandemic when I had COVID, I was extremely nauseous and nothing was helping me. I mean, I was really nauseous and I ended up taking Compazine and it was very effective for the nausea, but I had so many side effects. Essentially antipsychotic side effects. I said to myself... It was an aha moment. It's like now I completely get it because it was really uncomfortable. And I found myself saying, "What if I had to make this choice in an ongoing way?"

(07:50):

I don't know what I would've chosen, but I think, I guess I'm just trying to make the point that the side effects of these medications... There is nothing... I had never experienced anything like it.

Dr. Mette Ødegaard Nielsen (08:03):

No.

Dr. Lisa Dixon (08:04):

So anyway, I just wanted to share that. And really I think what you're doing is very important.

Dr. Mette Ødegaard Nielsen (08:09):

And sure. I mean, I treat patients with medication as well as I taper patients out of medication. I always meet the struggle with the side effect and have this discussion, what is the cost benefit? What is the benefit of the medication and what is the cost? And sometimes the patients choose, but if this is the cost of treating my voices, I'd rather live with them because this is so uncomfortable for me to have these side effects like no sexual desire, weight gain, like huge weight gain, and this glass bell feeling what a lot of patients really complain about not being really in touch with the world and in touch with their own feelings.

(08:50):

But that's also some of the things that we then struggle with when we tape that now all these feelings come back. And if you have had medication for 20 years dampening all your emotions, suddenly it can be a scary experience to have all these emotions. You don't know how to handle it. You can't remember.

Dr. Josh Berezin (09:09):

The clinic itself, sounds kind of like a compromise between these two views of a traditional psychiatry view about medications are helpful and we'll work on side effects, but you need to stay on these medications versus one that's actually acknowledging the reality of people who are taking the medications that side effects are uncomfortable or there may be other reasons why someone doesn't want to take medications in the clinic, is kind of taking that at face value and saying, "Well, what could a psychiatrist and other professionals role be in helping doing this more safely?"

(09:46):

So maybe a good segue to the paper, so tell us a little bit about your study participants and also what you were asking them as they began to taper down off of their medications.

Dr. Mette Ødegaard Nielsen (09:55):

The participants had to be stable, meaning that they had not been hospitalized for half a year to make sure that at least when we started out they were in a stable situation. That did not mean that they have to be without psychotic symptoms because quite a lot of them still had psychotic symptoms because the medication did not treat it, only maybe dampened it. And some patients even argued that it didn't help at all. And then they should not be forensic patients, but that was the main criteria, age between 18 and 65. But that's just technical reasons that it's very difficult every time you want to make research on people older than 65. That's Danish thing.

(10:39):

So that was the limit, 18 to 65 and they could have any all kind of use of drugs or alcohol, but not in a way that it compromised their ability to show up at the clinic. And then when they started out... Actually the way that we had these first three years is a little different than the way we run it today because in this first project, they actually came to the clinic and were in patients for three days to get to know the staff really well.

(11:12):

So they had two nights at the hospital and then they had a lot of questions. And what we mainly publish here is questions on what were the main motivation for trying to taper their medication and if they had previous experience tapering either on their own or with a doctor, it didn't matter. And then also a questionnaire if they thought they would succeed in either tapering or be medication free.

(11:40):

That was like a physiotherapist working with the body. There was a lot of offers in the first clinic, so that's not relevant for here, but that was what they did the first two days in the hospital. Now, they just come and see us for half a day and we ask almost the same question. And that's what this paper is actually about. What was the main motivational factors for the patients, their previous experiences and then their expectations for tapering.

Dr. Lisa Dixon (12:08):

Did you have any contact with the patient's psychiatrist or prescribing clinician?

Dr. Mette Ødegaard Nielsen (12:14):

They were referred by their own psychiatrist. So we announced the project also at meetings for patients. But to be enrolled, they should have a referral from either their own psychiatrist or the general practitioner. And that was sometimes done in a way where the psychiatrist wrote, he wants this referral. I do not recommend this actually where the psychiatrists were against the tapering.

Dr. Josh Berezin (12:47):

So for me, the biggest takeaway, we've talked a little bit about this already seemed to be that people were mostly motivated by decreasing side effect burdens. Is that the thing that you took away from the study as well or were there other top line findings that you think were important?

Dr. Mette Ødegaard Nielsen (13:04):

Definitely, I mean, that was one of the most important findings. But also I think there was quite a large proportion of patients who had this idea that they may not need... They have been happy taking medication for some years. They actually agreed that this was necessary for them for some time in their life. But now they felt they were in another place or they had this idea that they were dealing with the symptoms in other ways and that they could do either with very little medication or without medication.

(13:35):

And that was quite a big proportion having this idea as well, which I also think is very important to know as psychiatrists, because we see patients very sick and then of course they need medication and it help them. And then there's this... For some at least there's this, "Okay, now it's good. Hands off, keep your hands off. Now it's working and don't do anything."

(13:59):

I mean, I don't want to pass psychiatric diseases with diabetes. But anyway, it's very easy to do this comparison because if something changed, then you actually don't need that much diabetes medication either. And sometimes you actually change your diet and you wait that much that you don't even need it anymore. And that can also be the case for psychiatric patients. They develop. They go to psychotherapy for years. They are in another life situation. They just grow older more. They know their symptoms and know how to handle them.

(14:32):

And then of course they should try to do that with at least medication as possible. But of course, that's also very important that we do have this discussion with the patients that it comes with a risk of having a relapse. And we also do have this very long talk with them. What did you actually experience when you were psychotic and what would be warning signs? What should we be aware of? What would you be aware of? Because then maybe we are at the level where we should stop for a while.

(15:04):

In this project, we had patients who came really down to a third of the medication and then stopped. And then they stopped there and we decided, "Okay, this is where to be. Have a break. And if you still feel like, come back in two years." And then we have had some of them who came back and tried to go further down with [inaudible 00:15:26]. But yeah.

Dr. Josh Berezin (15:28):

What did those... So you mentioned there's a sub cohort of people who had tapered or discontinued in the past and re-experienced psychotic symptoms that they felt were troubling or got in the way of their lives or led to an inpatient admission or something along those lines. And so those were prior experiences though, and they were now coming to the clinic to try again. Did you learn anything specifically from that group that was different from other groups?

Dr. Mette Ødegaard Nielsen (15:58):

Well, I will say that as a psychiatrist, you were always more aware if people have tried to taper and they had a relapse because then you will say, "Okay, this may increase the risk that this will happen again." And that does not mean that it happens every time. We haven't looked specifically into data if those who had a prior relapse in a higher degree had a relapse again. Also, some of these patients actually had this idea that they only wanted to go down to decrease the dose. They don't want to go out because they were so scared of relapse again.

(16:36):

So actually we've had some patients where I thought I would think they could manage without medication and they say, "I don't want a day. I don't want to try now. I'll go here. This is the level, I'll stop and then I'll reconsider. Maybe I'll come back at some point." So I don't think we have this knowledge that if this has happened before, then it will not be possible because it was possible for some patients, but also some of those who did have a relapse had it again, even though we tried to make it more gentle tapering than they did themselves.

(17:14):

I think that's what our new project is focusing on is can we at any point try to predict and relapse early in the phase? Are there any indicators that can tell us if it's a good idea to taper or not taper? And by now there's not really any to hold on to. It has to be, yeah.

Dr. Lisa Dixon (17:38):

Are the medications all the same in terms of the impact of tapering or are some worse than others?

Dr. Mette Ødegaard Nielsen (17:44):

Yeah. I think I get your point that when I looked into the data for the tapering period for this first cohort, I was astonished that none of the patients who received clozapine actually got out of medication without relapse. But in our new cohort, we have two patients that actually have done that and are now during an observation period for more than half a year with no signs of relapse at all. And when you look into the details on these patients, you could consider if the clozapine was started maybe a bit early, that they were not normally tried a lot of compounds and then put on clozapine.

(18:31):

But that was my only like, "Wow, that was amazing." But now we have other experience and we still have too few numbers to do a statistical analysis on this. But of course when we plan the tapering, we need to look into the pharmacodynamic of the drugs because especially clozapine and quetiapine are drugs that when you're in the low doses, you still have to go very slow, even though your percentage are very low withdrawal symptoms can be really outstanding even under low doses, the last couple of milligrams actually.

(19:11):

So there's definitely differences also in the effect that what happened to people because some of the really like the old dopamine antagonists and the hardcore dopamine antagonists when you have the dose, you saw people became so much more lively. And then the sad thing is that around weight gain, that losing weight was almost not happening until they were on the really, really low doses of out-of-medicine.

Dr. Josh Berezin (19:43):

So one of the other aspects of the paper is you're asking people about what their expectations are going into the taper. Do you think you're going to be able to taper down? Do you think you're going to be able to go off medications completely? Were you able to tie some of those with people's courses that people who expected to be able to taper off all the way actually did, or people who expected to taper a little bit actually ended up going all the way off medications?

Dr. Mette Ødegaard Nielsen (20:10):

Well, yeah. In this paper here, we don't have any longitudinal data and it just been accepted for publication. But the problem is that this first cohort, the tapering period was only half a year. And if we

have to do the tapering as slow as we want to, the percentage that was for whom it was actually realistic to be at zero were less than half of the cohort.

(20:35):

So that's why in our new study, we have extended the period for tapering to a year because then it's actually possible to come out of medication. So the problem with the data from the first project is that the time period for half a year is too short for most people to actually get out of medication. So this outcome we couldn't really look into even though it had been interesting.

(21:01):

What we saw was that some patients were really low in medication after half a year. Then they were invited just to see us after a year. And a few of those who were low had continued tapering at their own psychiatrist and then they were out of medication. So there wasn't a few ones who were doing without medication and tapered the rest with their own psychiatrist. But now the aim is that people who want to should have the possibility of getting out of medication within a period of around a year. And if sometimes necessary it'll be 15 months or something not to be too quickly in the last part. And then we follow them for another year. If they go out of medication, we'll follow for another year to see if they get any relapse.

Dr. Josh Berezin (21:47):

Lisa, I don't know if you remember, but before we started the podcast together, I was working on a paper that you were involved with that I don't think went anywhere about shared decision making. And so I loved seeing the framework of shared decision making in this paper and in our discussion, the whole clinic seems like it's shared decision making come alive in a clinic. The whole idea is based around a shared decision making model. So I was wondering if you could just elaborate a little bit on that aspect of the clinic or the paper.

Dr. Mette Ødegaard Nielsen (22:24):

Yeah. Well, the program in the clinic is actually that this personal nurse, the contact person will get a very close relation with the patient. So they talk on phone once a week and they meet in person in the clinic where the doctor will also be there once a month. And by doing this, we get this close feeling, what is important for this patient? How is the life circumstances?

(22:51):

Sometimes there's a father dying suddenly during the tapering period, and then it will be natural that, "Oh, there's so much stress in my life right now," so that they end up agreeing the patient and the nurse that, "Actually maybe I should have a break. Maybe I should have one or two months without tapering further because there's so many stressful things going on and my sleep is bad. I don't know if that's because I'm almost on half the dose or if it's because my father died. It could be both."

(23:24):

So there's a lot of discussion and talking and getting to know each other. Also, knowing the strategies that the patient has. And sometimes the patient comes and say, "I don't want to go further." And we think that it could be an idea, but if the patients feel that this is not what they want, it's of course their decision. And sometimes the patient comes and say, "I really want to go further." And we may not think it's a good idea.

(23:52):

If we know the patient well, we can have this discussion. And sometimes the patient end up agreeing and say, "Yeah, maybe it would be okay just having another month to observe and stabilize." And sometimes the patient does not agree, and then we will follow the patient. As long as we have this close connection, we can have these decisions. That can also be a problem that sometimes the patient withdraw from the clinic or from the contact with us.

(24:25):

And then of course, we must say that we cannot do any further tapering. If they do not have this close contact, we don't feel able to take these decisions with the patient.

Dr. Josh Berezin (24:37):

So as we start to wrap up, is there anything else that really stood out to you from the study in the paper?

Dr. Mette Ødegaard Nielsen (24:44):

I think there was one point in the paper, I don't know if it's of interest for your readers, but we philosophized a bit about it because there was this, that patients had this high expectations to being medication free. Actually, there was about 80% almost that expected to be medication free. We didn't ask the clinicians what they expect. We do that in our ongoing study and the clinicians do not expect that many patients to be medication free.

(25:16):

So our expectations are that it will be a success for maybe one out of three. That's when we meet the patients and our real life data shows that it is not one out of three that gets medication free without relapse in our studies. It's less. And then you can of course-

Dr. Josh Berezin (25:38):

Less than one on three?

Dr. Mette Ødegaard Nielsen (25:39):

Yeah. Right by now. Then you can of course discuss why. And I think an important thing is that the patients attending our clinic is not necessarily representative for the whole psychiatric population or the whole schizophrenic population because they need to show up. So if they do not show up, if they're not able to show up and collaborate with us, then we don't want to go into this work helping them taper.

(26:06):

So that means that they have to be a little stable and show up. Almost all our patients do that when they enter the program. But then also there's a lot of tapering going on in Denmark in the normal clinics, in the normal outpatient clinics at the general practitioner even, and sometimes the specialist and the private psychiatrist that's not affiliated with the hospital, but in the clinic. And they taper patients as well.

(26:38):

So the patients that we have referred in our clinic are probably the more complex ones. The ones where the psychiatrists themselves say, "I'm a little unsure this is a good idea. So I'll better put them in the specialized clinic where they have this special knowledge and these resources for close contact with the patients." And that may be why, because when I look into the data now, and it's ongoing, so it's all the

time getting more data. But there are quite a lot of relapses. The good thing is that they're not that severe. Mostly we get them before they get really severe.

Dr. Lisa Dixon (27:20):

Yeah, that's kind of my question I think is what is the meaning of relapse in this context? And as I am thinking it, I think what it means is return of psychotic symptoms. But of course I think that's not all the same either. So that for some people there may be modest return of non-bothersome symptoms or for other people they might be very dangerous or scary or uncomfortable. And so it seems like it's important to think through not just the risk of relapse, but what that relapse might look like and feel like.

Dr. Mette Ødegaard Nielsen (28:04):

Yeah. And I think we have different kind of relapse because we have the relapses where it's exactly the previous times they had psychotic symptoms that suddenly hallucinations get back or suddenly these delusional ideas take a lot of room and causes so much anxiety and so much occupation of the mind that it affects the ability to live the life that they lived when they were on medication. And then when patients themselves can see that. And I will say nine out of 10 of our patients with relapse, they can see it themselves.

(28:51):

Then they actually agree to start medication. We have had a couple of patients where they did not see it themselves and it was a little critical because they didn't sleep at all almost and had these ideas that they should do all these things in the world and were getting really more and more sick. And then of course we need to help them. We have only had one or two of these cases among 150 patients where it was getting a kind of, "Okay, you need help. You don't want help. We really need to help you."

(29:31):

And then it was not that terrible. But it was still... Yeah, we had hoped it would be more smooth that we could agree because then it's not shared decision-making anymore when that happens. And it has happened twice, I think.

Dr. Lisa Dixon (29:49):

It's an impressively small number.

Dr. Mette Ødegaard Nielsen (29:50):

And I think that the reason why it is so small is because of this close contact. I mean, these nurses we have, they are so experienced and they're so good at making these connections to the patients and talking with them in a way that the patients can actually see that this is for their own good. And yeah, you are right. Really, this is too much for me now when this is going on. I better have a little medication and then feel better because this is worse. And then often this is also the results from the papers just accepted that when patients need to go back on medication or they cannot taper anymore and we need to increase the dose, almost all of the times we end up at a lower dose than when they started out.

(30:43):

So they stabilize on a lower dose. Few times, we had to go higher or sometimes patients changed medication and then at least got rid of those side effects that they were really annoyed about.

Dr. Josh Berezin (30:57):

So just to wrap up, I mean, it also seems like this can be rewarding work for psychiatrists and maybe rewarding on the patient side as well to develop a more collaborative relationship. But I'm wondering if you have any reflections on what it's been like to take this stance as part of your career?

Dr. Mette Ødegaard Nielsen (31:24):

It's definitely rewarding to see patients who have been in a prison of side effects. Honestly, some of these patients we have seen have so many side effects that all these ataxia, tremor, rigidity, all these things. And when you decrease the dose, they loosen up and almost... Not even only almost, but they turn normal. Their body turns normal again. They're not having all these side effects anymore. And even though they still need medication they can do on a dose whether they do not have these side effects. And seeing these patients have this resolution of these side effects, that's so amazing. And they're very grateful getting their body back.

Dr. Josh Berezin (32:12):

Well, thank you so much for joining us and telling us about the clinic and the paper, and I'm really looking forward to seeing some of the follow-ups that you mentioned and really appreciate you taking the time today.

Dr. Mette Ødegaard Nielsen (32:26):

Yeah, thank you very much for letting me tell you about the Danish Clinic here.

Dr. Lisa Dixon (32:32):

We are very grateful to hear your perspective and I think share with us in a very honest and real way what it's like to be in this role. Thank you.

Dr. Mette Ødegaard Nielsen (32:46):

Thank you very much.

Dr. Lisa Dixon (32:47):

Very illuminating. I really enjoyed that interview. So we conclude. We invite you to visit our website, ps.psychiatryonline.org to read the articles we discussed in this episode, as well as other great research. We also welcome your feedback. Please email us at psjournal@psych.org. I'm Lisa Dixon.

Dr. Josh Berezin (33:08):

I'm Josh Berezin.

Dr. Lisa Dixon (33:09):

Thank you for listening. Talk to you next time.

Speaker 4 (33:13):

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