

Podcast – Pharmacy Matters: Expert Tips for Psychotropic Medication Monitoring

Interviewer: Keith Willoughby, CPRI Planning Analyst

Interviewee: Ross Evans, CPRI Pharmacist

The following podcast is part of the Children’s Mental Health Week series released by CPRI in London, Ontario for the Week of May 2-6. CPRI – the Child and Parent Resource Institute provides highly specialized assessment and treatment services to children and youth with complex mental health/developmental disabilities. The education and learning services at CPRI supports evidence informed learning for individuals and organizations working in child and youth mental health and developmental services with the goal to improve the lives of Ontario’s children and youth. Children’s Mental Health Week is a provincial initiative aimed at increasing awareness of mental health issues faced by today’s children and youth and decreasing the stigma that may exist. In addition, it is an information sharing initiative to show that treatment can work and there are always possibilities and opportunities to explore. There is always hope and always support.

Disclaimer: Please note the following disclaimer. This podcast series is not intended to be medical advice and all medical concerns and questions should be directed to the appropriate health care professionals

Introduction: Today’s topic is Pharmacy Matters: Expert Tips for Psychotropic Medication Monitoring. Keith Willoughby will be interviewing Ross Evans who is the chief pharmacist at CPRI. Keith Willoughby is a planning analyst with the Applied Research and Education Department at CPRI. He is currently coordinating research associated with the development of MedWise, an application currently being developed in corporation with CPRI to improve the safety of children and youth who have been prescribed psychotropic medications. Ross Evans has been involved in many projects and committees tasked with improving medication safety for youth. He has helped develop a rapport on implementing international guidelines for the use of psychotropic medications which has informed standard of care recommendations for the use of psychotropic medication for children and youth in Ontario’s residential facilities. Ross is also contributing significantly to the development of the MedWise app for tracking psychotropic medication side effects.

Interviewer: Hi I’m Keith Willoughby. I’m a planning analyst at the Child and Parent Resource Institute and I am having a conversation today with Ross Evans.

Interviewee: Hello Keith, I’m Ross Evans. I am the chief pharmacist here at CPRI.

Interviewer: Thanks for taking the time talk to us today Ross. We have a couple of questions here about child and youth use of psychotropic medications and hopefully we are going to get some useful information from you that might be informative to caregivers. The first question that I want to ask you is, ***psychotropic medications seem to be being prescribed to youth at an increasing rate. How do you monitor the side effects of these medications in clients?***

Interviewee: Monitoring is extremely important and I think first of all it is important to understand that there are different types of monitoring. There is monitoring for efficacy of the medication and there is monitoring for side effects. So efficacy is seeing how well the medication is working for the conditions being treated and side effects are the negative aspects of what the medication may be causing. So there is that distinguish in monitoring. We are developing a side effect application that helps to track the side effects, the negative effects. Within, when you are tracking or observing or monitoring side effects, there is objective monitoring and there is subjective monitoring. Objective monitoring is perhaps an example would be like a lab test where you are finding out from blood work how the liver enzymes are doing or how the hemoglobin C for diabetes but the app that we are working on is more about subjective monitoring and that is observations. Observations are key. Observations from the client, observations from the family, observations from the other caregivers, observations from the treatment team. All of those observations are key data to determine how well this drug is working, but in terms of side effects it is any negative impact that it is having on the client. So probably the steps in monitoring would be first of all you find out baseline how someone is doing. Before they even start the medication, how is that client doing, how are they feeling? The reason why you want to do that is because if a week later once they start the medications they are reporting that they are fatigued and low energy well if they were fatigued and low energy before they started the medication it might not be the side effects. So first of all, you have to know what you are at, at baseline and then you make observations. For the client and all the other people involved are there any potential negative effects that are happening? Now if those observations are not noted or documented, it is easily forgotten or it is easily mixed up. Technique or some sort of system for documenting those observations is important and also important is communicating those to the treatment team. The treatment team involves the client, the family, all the treatment team members so that might be the prescriber obviously, a pharmacist, a nurse and direct care givers. Here at CPRI, when someone is here residentially, child and youth workers will be involved with the client and help them with treatment. People make observation and it goes out to the team and the second last step would be to evaluate that information and

determine whether or not it is a side effect and whether or not the treatment plan should be modified based on that. It is very important to realize that all of the side effect monitoring is based on trying to update the risk benefit ratio for the child or youth who is taking the medication. The risk benefit ratio is the risk of using the drug versus the benefit and if that is a positive thing, if it looks like the benefits outweigh the risks then you want to be taking that medication. That decision may have been made by the client or by the family; however, as you observe things, if you observe some negative effects, part of the risks that are actually happening, that could change the risk benefit ratio. So this is always a fluid paradigm, it could change. It's important to be monitoring it and be aware of that and to make changes as needed.

Interviewer: A related question - so part of the pre-interest in this is a general growing awareness amongst the public that there seems to be a dramatic increase in the rate in which children and youth are receiving psychotropic prescriptions. Some of our research at CPRI indicates that psychotropic medications are amongst the most prescribed categories of medications for children and youth currently. I think this causes parents just general concerns to know that there is a dramatic increase in the last 10 years over the rate of which these drugs are being prescribed. *Can you talk about why you think the prescription rate has increased and whether or not parents should be concerned about that?*

Interviewee: So what you got is children and youth, who are developing, their brains are growing, their body is growing. You got psychotropic drugs that have potentially severe side effects and you got the rate increasing over the last 15-20 years very significantly. Should there be concerns? There definitely should be concerns. Concern is healthy when there is a potential risk, however, concern can put skepticism and it can go to all kinds of lengths that can also dissuade people from utilizing things that can really help them. The other side of this is that the incidents of severe psychiatric, severe behavioural, emotional and developmental problems in children and youth seem to also be rising. If that goes untreated, the projection into the future can really negatively harm a child's future, a child's life, a child's health. There are innovations that are available that have been shown to be effective with the right client, with the right diagnosis. The important thing is to ensure that the right innovation is used with the right child at the right time and that it is monitored because everyone is their own unique individual, made up of their own unique genetic makeup. Medications effect different people in different ways and the reason why it needs to be monitored so close is it's not predictable necessarily. If you take a research study and you take a whole group of clients, statistically the side effect will happen in this percentage of people. You don't know if that is going to be you,

something that may not happen to most people because of your own genetic makeup may happen to you. Negative side effects are something that have to be monitored, it is definitely something that a person should be concerned about but concern also should be for the opposite side of that and how well the child or youth is going to do on that current path. If those two things could balance then a risk benefit ratio can carefully be determined and if it's monitored properly then there is a place for psychotropic medication interventions. It could do tremendous benefit for certain clients but a healthy concern about this is appropriate, it should be part of every consideration.

Interviewer: Absolutely. So in the context of understanding the risks and health concerns that parents may have, one of the big ideas in this space that gives people pause is that a number of these prescriptions of this increased proportion of prescriptions that are occurring are what are called off label prescriptions. Research suggests that this may be a significant proportion of the prescriptions. *Can you talk a little bit about what an off label prescription means and how a parent could understand what it means that their child may have an off label prescription?*

Interviewee: Yes. So on that label that is the official approval, that is granted by the regulatory body of that particular country - Canada, US, there are labels that have been approved. The studies have been sent in by the company, the research has been documented, they have been approved for this purpose and in this population. It costs less money and it takes less time to study medications in adults than it does in children and there are less risks for the company. In Canada especially, I will talk about the States later, most of the time drugs are marketed and approved based on adult dosage. That means that the only thing on the label is adult dosing. However, there is no law that prevents a doctor from taking the clinical literature, the evidence based literature and seeing that it has been used successfully based on evidential treatment or case studies and using that medication in a different population. There is nothing illegal about that or wrong about that, however, it may not be on the label because the company that developed it doesn't want to spend a bunch of money trying to test it in children. So off label has this connotation that it is wrong to use it in that way, when really what it is, is signifying marketing reasons why and costs reasons why it is done that way. In the United States a number of years ago - maybe ten or more years ago, they came up with a law that said that they could extend their patent. I think it was the manufacturers of the medication that could extend their patent by six months if they did experiments or research in children or youth. That increased the amount of information and research data that was happening because it had a monetary benefit to their companies. There is more data out there in the States and you will probably see more official indications for psychotropic

medications in the United States then you will in Canada, but again, if you have a child and youth psychiatrist or another prescriber who is using the evidence based literature to look at potential treatments and you are getting an informed consent process about why this medication could be good, why it could be a risk, and what the other options are then that is a legitimate process that could really help you. I think that's a little bit of an explanation about it.

Interviewer: Ok, thank you. Clearly there is a lot to understand about these sorts of medications. In general psychotropic medications, many of them do not produce an immediate improvement but often take time to take effect. *Can you talk a little bit about this and why it is important, how this underscores the importance of monitoring and tracking side effects and following the instructions associated with your medication provided by your physician.*

Interviewee: Yes and that is true that for most psychotropic medications it takes days to weeks to get the full effect. Now I am going to put a revise on that though, it's not even every psychotropic medication that is like that, there are other medications as well. However, in general that is the case. For example, an anti-depressant like an SSRI (Selective Serotonin Reuptake Inhibitor) could take 4-6 weeks before you get the full effect of it in treating depression. If it is not at that right dose, you may have to up the dose and go another 4-6 weeks before you get the full effect. So that can take time and if you are a client or a family member that doesn't understand that, you are looking at that and three weeks have gone by and you are not seeing a lot of improvement on that, you may be seeing side effects that happened almost immediately. One of the most common side effects with SSRIs when you are first start them will be upset stomach, dizziness which can be upsetting to the client, without the knowledge that these types of side effects, typically, not only happen before the medication becomes effective but also tend to be temporary. A number of side effects, not all of them but ones like these tend to go away within two weeks, sometimes within days, sometimes within one day, it depends on the person - some people do not get them at all. So if you understand that or looking at a bit of a longer view, about the risks of the conditions, it helps very much that you have listened to the prescriber about that, heard what they said, and can apply it to your situation. In this situation, what can I do for now to get over the upset stomach which aren't severe and aren't long lasting. Maybe you can get some advice about eating smaller meals more often for the first while. Sucking on a hard candy and staying hydrated, all those things tend to help with the upset stomach. If you are getting dizzy be aware that when you get up from a sitting or lying position do it really slowly because you are more prone to getting more dizzy and potentially falling. Advice like that might help you get through that initial part and the understanding that the efficacy comes

later might help you as well.

Interviewer: Thank you. Further on understanding adhering to dosing schedules and taking your medication, *what advice can you give from a pharmaceutical perspective if a patient misses a dose of their medication?*

Interviewee: My best advice for someone who is not sure because there are so many variations of this, it depends on the particular medication, it depends on how many times a day you are giving the medication and it depends on the dosage form because sometimes it is long acting or it is an immediate release. So because there are so many different factors with each situation, my best advice is to contact your community pharmacist who is very accessible by phone and ask him/her what would be the best in that situation if you are not prepared ahead of time by your health care professional for that situation. Even if your pharmacy is closed, say if you got one that is 9-9 and it is after 9pm, 24 hour pharmacies even if you are not their client will give you help with that. That would be a really important thing to remember.

Interviewer: That's a great tip. *Relatedly, what tips can you offer to parents and direct care givers on safe medication handling, including specifically storage and disposal of these medications?*

Interviewee: That is an important one as well. When I think of storage I think of three things: storing it in the right environment to keep the product maintained, I think of storing it in a secure vault and I also think of storing it in a way that enhances your ability to take the medication properly. So when you are talking about storing it in the right environment, heat and humidity can take away from the potency of the medication and make it so it doesn't do what it's supposed to do. You want to keep it away from humidity so you'd keep them in the bathroom which use to be the traditional place to keep it and it probably isn't the best spot with the shower going. Keeping it in a hot car in the summer is a no no because most medications are best to be stored at room temperature and if you get it outside of that then you could have degradation of the product. Room temperature is typically between 15C-25C but for sure below 30C. Now some medications it's important to know are required to be stored in the fridge. If that's the case it will be marked that way and you'll know that and you keep it in-between 2C-8C in the fridge. Medications, very few of them should be frozen. There are a few vaccines and a few things that are kept frozen, those are very specialized cases. You don't want it kept outside of the car in the middle of winter as well. The second thing that I mentioned was storing it in a secure way. Now there has been many instances where children have gotten into medication that's another family members. It is one of the reasons

why child proof caps are used, there is also the potential for siblings of someone who is getting the medication to get into the meds. So it is good to secure it in a way that's high and up away from children and youth. The other thing to mention about this, in our society people are using prescription medications more and more for recreational purposes and that happens in regular every day families. Any family could be tempted, one of the members might be tempted that way so someone in your family that may be tempted that way it is good to keep tabs on that as well and it's best for everyone's health. You want to avoid the accidental or wrong ingestion of the product for someone that is not intended for it in a way that's not intended. The third thing that I think of when I think of storage is kind of something that you maybe usually wouldn't put in this category but I think of taking the medication, making it stored in a way that makes it easy to take the medication. And by that, if you are taking it at bedtime, the easiest way for you to remember it is on your counter beside your bed or in your drawer beside your bed and that's a good spot to keep it. Everyone has their own habits but if there is a natural spot where you remember, noncompliance is a big thing but noncompliance is a fancy word for forgetting to take your medication on a regular basis instead of just once in a while or not taking your medication for other reasons and that defeats the purpose of the medications. It's very important to take it regularly. So if you can enhance that, I have medication myself and I know that not only is it easy to forget to take a medication but it's also easy to forget that you have taken the medication because it's almost like a loss of memory, you take a medication automatically and then half hour or an hour later, was it yesterday I took it or was that today? And then you're in danger of double dosing or missing the med so using something like a dose set where you have the dose marked off by day and you can see if that dose is there, then I haven't taken it yet. A pharmacy may be able to put it in a blister pack for you if you find that handy. Also, a dosing calendar or medication administration record of some kind, I mean in facilities we use what is called a MAR – Medication Administration Record and when a medication is administered you initial beside it whoever administered it and you know that the dose was given. Some type of calendar or a way of doing that yourself. So if you have those types of tools right there where the medication is stored, that's part of storage in my view, to enable you to administer it properly.

Interviewer: I was just going to ask you regarding disposals, so ***suppose you do have to dispose of some medication that you are no longer taking, how would you do that safely?***

Interviewee: Well disposal is something that should happen ideally when you are done a course of treatment even if there are medications left. If you are done with

that medication or if your medication has changed it is good to get it disposed of quickly rather than just sitting there. If it is a medication that you need once in a while and it goes expired, get it disposed of at that point. The way things used to be disposed is not the way to do it today. Medications used to be disposed by flushing them down the toilet, by washing them down the sink, by throwing them in the regular garbage but we found that over the years, environmentally this is not a good thing. They can get into the environment, they can get into our waters and with mass people doing this it then creates problems for animals and people. Also, there is a potential that someone might ingest it if it is in a garbage as well. So the best way to do this, and every community pharmacy is doing this, is to bring your meds that you need to dispose of to your community pharmacy and they have contracts set up with hazardous waste disposal environmental companies. They will put it in the proper bucket and the company will take it away and dispose of it in an environmentally friendly manner and in a way that is safe – that's the way to do it.

Interviewer: You spoke a little earlier about the importance of understanding the risks and benefits of the medication that you may be taking and you also raised a very good point that the primary place that a lot of people go for information today is the internet and of course there is all sorts of information there and some of it is useful and will help you and some of it is less useful. *Can you talk about some places where good information about psychotropic medication for children and youth might be available on the internet and can you also maybe provide us with a bit of a framework for how we might be able to tell whether the information we are looking at is good and useful information or whether we are travelling off down the garden path when we look at information on the internet?*

Interviewee: I think that is a very good point. The internet is a great place to do research and it is a good place to do research on medication as well, however, you always have to consider the source so that's the key framework that I would say - the source of the medication information. If it's from the National Institute of Health in the States, if it's from the Canadian Pediatric Association or one of the pediatric pediatrician associations or one of the psychiatrist websites like the Child and Adolescent Academy in the States or the Canadian version, some pharmacy schools or universities for example the Halifax university in Nova Scotia which is Dalhousie has some very good pharmacy information in there. There are some drug interaction resources out there – now much of this medication information starts to get, depending on where you go, it starts to go more towards health care professionals but a lot of them will say – here is for clients and patients and here is more information for health care professionals but the key point in all of this is that the source is important. Now if you go to an individual doctor source that may or may

not be a good source, you don't know the particular meanings of that individual you don't even know for sure because of the nature of the internet if that person is a doctor necessarily unless you know them personally and you know their website. So that is the dangers of the internet, you can get a certain point of view even a point of view that has truth in it but thinks it is the only truth but neglects other situations. The other thing I wanted to mention was that a lot of the really good information is subscription based, so there is real good information if you want to pay a little bit of subscription fee too if you are really interested – things like drug interaction databases or natural medication databases or just general prescription databases.

Interviewer: *If I was on the internet and I found some information about a medication that I was concerned with and I wasn't sure about its quality or I wasn't sure about its importance. Is that a question I could bring to my pharmacist or physician?*

Interviewee: Absolutely, that would be the thing to do. Bring the information for further questioning, for some further understanding and determine whether in this context whether it was accurate information or not because you are coming in with a personal situation and that pharmacist or doctor is aware of your personal situation as oppose to the internet information which is very non-personal – they don't know you.

Interviewer: *Alright. Are there any other important pieces of advice that you can offer families, caregiving teams or young clients who may be listening to this today?*

Interviewee: I think my most important advice for this audience today that just comes to mind right now is to become actively involved in your own decision making about your own health care because this is your body, this is your health and this is your future. You know when you are young you think you are going to be healthy forever or you think that things are minor but whereas health problems can influence your life so it's important to take that seriously and make decisions based on understanding, asking questions, making sure that you are OK with that. IF you have a nagging doubt, if you've got a question in mind, if you want to understand the risks better, that information should be given to you. You can ask for it – your health care professional will be glad to give it to you if they have to come back to you later because it is an involved question, they can do that but you need to be involved in deciding – is this right for me, understanding the risk benefit ratio. What are the risks if I don't take it, what are alternative courses of therapy that I could have besides this medication we are talking and what about this medication, risk- benefit, so I can make an informed decision. Then if a child or youth is involved in that decision making process it is a little easier to be involved in the monitoring as well.

You have a good understanding, you know what the negative effects can be, you know what the positive effects can be – it is a little easier to monitor and say hey, wait a minute this has happened I am going to communicate this. With those questions you can understand what is a serious side effect potential, if a sign of something potentially serious can come up you know that that is a flag and you have to deal with it right away and if it is dealt with right away then the problem can be avoided or minimized which really increases the safety profile of using that medication. This whole process is integral to using these medications in the way that maximises their safety and also maximises their effectiveness because you are watching how well they are doing too. I like to give a little example of my daughter. For some people this type of involvement comes natural, so my daughter was 4 or 5 years old and she had warts on her hand and she was going into the doctor's office to get treated for it and my wife brought her. The doctor started getting the wart treatment prepared and she said what are you going to do to me? She was 4 or 5 and she was talking to the doctor directly and not asking mom to tell her and he said well we are going to do a treatment to get rid of your warts and she said well what is the wart treatment? He said liquid nitrogen. She said what's that? And he explained that and then she said is it going to hurt? He said it is going to sting at first and it might sting for a while later and she said is there a way of it not hurting and he said well...yeah we could have given you EMLA cream which numbs the area. It would have had to been given an hour before the appointment however. She said let's do that so mom took her out of the appointment, they made another appointment and they did. And she was at 4 or 5 advocating and getting involved and asking questions about her own health. So if a 4 or 5 year old could do it then you know a child or youth can get involved. Other personalities, you know I have other children and they wouldn't react the same but with your reporting team which includes your parents which includes your trusted family and hopefully you develop a trusting relationship with that health care professional as well, particularly the prescriber who you are talking to about it, your pharmacist maybe, your nurse, your direct care staff if your in residence. If you can develop that relationship but not be afraid to ask questions because they should be answered. By law nothing can go in your mouth, no medications can go in your body unless you consent to that - as a child, youth or adult. That is very important and important to remember that you are in control of that. You know the only exception to that is if the person doesn't have capacity to understand. Children and youth can understand a lot of things so as a child and youth get involved with your family, get involved in your health care and you are going to see better benefits and its going to help your future that would be the main thing I would emphasize.

Interviewer: Thank you and I will underscore too that there's no minimum age for consent

so your four year old daughter of course is in a position to advocate for herself and that's a good example. I'd like to thank you for providing an informed pharmaceutical perspective on these issues and thank you for taking the time to speak to our families and their caregivers on Children and Youth Mental Health Week.

Thank you for listening to this podcast provided by CPRI. Be sure to check out Childrensmentalhealthweek.ca for more resources.