Liver Transplant: Improving Outcomes for Medication Adherence

Medication adherence is critical to the long-term health of liver transplant patients.

Yet, adjusting to the demands of a complex regimen and coping with the psychosocial issues commonly associated with transplantation can negatively impact disease management, with average rates of nonadherence among pediatric liver transplant recipients exceeding 50% and accounting for nearly half of acute rejection episodes.

Children's Mercy Kansas City has created the Liver Transplant Psychosocial and Adherence Promotion Service to aid in facilitating long-term disease management, enhanced patient well-being, and optimal health outcomes.

Jamie L. Ryan, PhD, is joining us to discuss this integrated service and share how Children's Mercy is treating the whole patient by providing comprehensive psychosocial services as a part of standard liver care.

Featured Speaker:

Jamie Ryan, PhD

Jamie L. Ryan, PhD is a Pediatric Psychologist and manages the Liver Medication Adherence Program at Children's Mercy Kansas City. Dr. Ryan received her PhD at Oklahoma State University in 2013 and completed her fellowship in Pediatric Psychology at Cincinnati Children's Hospital Medical Center in 2015.

Learn more about Jamie L. Ryan, PhD (http://www.childrensmercy.org/Clinics_and_Services/Clinics_and_Departments/doc=22247)

Transcription:

Dr. Michael Smith (Host): Our topic is "Liver Transplant: Improving Health Outcomes Through Adherence Promotion". My guest is Dr. Jamie Ryan. Dr. Ryan is a pediatric psychologist and manages the Liver Medication Adherence Program at Children's Mercy Kansas City. Dr. Ryan, welcome to the show.

Dr. Jamie Ryan (Guest): Thank you for having me.

Michael: Who benefits from the Liver Medication Adherence Program?

Dr. Ryan: That's a great question. Honestly, I'd like to think that everyone kind of benefits in terms of our patients and families as well as our team. So, in terms of our families there's potential for an integrated service to allow for early identification of some of the risk factors that we know can be commonly associated with non-adherence so that we can kind of be more preventative as opposed to reactive for helping those families, either getting them set up with services or providing some additional

resources to prevent non-adherence from occurring. It also gives them increased access to a psychologist at the point of care. So, it helps to minimize or prevent some of those barriers to receiving some of those services for families. From my standpoint, being in the clinic allows for possible reduction of some of the stigmas that can be associated with receiving psychological intervention or support by allowing me to educate families on some of the possible impacts on transplantation on psychosocial functioning and it allows them to see psychologists as really part of a larger team as opposed to this more distance person who they see once the team identifies that there's a problem. Again, kind of going back to more of a reactive approach. It allows me to facilitate that family engagement when concerns are reported so I can be more effective as opposed to putting out fires once something has become really significant and is clinically impacting their daily functioning. From my physician colleagues or transplant coordinators, they think it helps building some of that communication – ways to talk to patients about adherence--and allowing them to acquire or refine some skills to generally be more effective in talking with patients about the importance of taking their medication and possibly being mindful in terms of the clinical decision making on potential side effects, if that's an issue for a family or the number of pills that certain medications or a dose is going to require of a family.

Michael: That brings up a good question. Obviously, liver transplant patients are on multiple drugs. Is the adherence an issue more of side effects or is it just so many pills or a combination of both? What do you usually see?

Dr. Ryan: It runs the gamut. There are quite a few barriers which I think is what makes it hard to think of it more from a preventative standpoint unless you're actually assessing for some of the barriers to adherence. It can range from the side effects which I honestly don't see quite as often. The number of pills can become a barrier. If a kiddo has difficulty swallowing pills, if there's general oppositional behavior, that can become a barrier as well. Poor organization. The most common one is just generally forgetting. It kind of interferes with daily activities, especially if post-transplant, they are starting to feel good and we are encouraging them to get back to their daily routines and becoming more active which is great but being away from home can kind of create an additional barrier to being adherent to their medication which requires strict adherence to a dosing schedule.

Michael: In this process, how important is it and what's been your experience when you really involve the parents and the family in understanding the medications and understanding how important they are and how important adherence is? What's been your success in teaching that to the families?

Dr. Ryan: I've had pretty good success. I think explaining why. For instance, for this population, a 12-hour dosing schedule, why is that important? What does it mean if you get off by a couple of hours and how, over time, it can impact whether or not they're still in a therapeutic range for their dose. I think it means something to families in terms of you can normalize non-adherence because it's difficult to expect 100% adherence 100% of the time. So, it gives them leeway to know that they're not expected to be perfect. Would we like them to? Absolutely! But, they're human and life goes on once they leave the clinic. So, allowing some of that to come out encourages them to be adherent but also gives them permission to express concern or readily admit if they're struggling with being adherent on occasion.

Michael: I think I like that, Dr. Ryan. That approach of "we want you to be as close to perfect as you can but you have busy lives, things go on and we're not expecting perfection". I think that maybe that takes some of the pressure off. Do you see that with the parents and the family?

Dr. Ryan: Yes, I do. I think it helps, for me, I know I can tell a family anytime I've had a course of antibiotics prescribed for me personally, if I haven't been 100% adherent and taken the full course, technically, I guess I would be considered non-adherent. While I was well intentioned, I started feeling better and that's why I didn't think to take it. I think that's the case for a lot of our families. They are very well-intentioned and then, other things kind of interfere. So, by allowing them or normalizing some of these difficulties, it one, I think promotes adherence but it also encourages them to just be more expressive of any concerns as they might arise.

Michael: So, you manage the program which is "The Liver Medication Adherence Program at Children's Mercy". How long has this program been in place? How is it different from a similar program at another hospital?

Dr. Ryan: It's been in place, I started in September of 2015, so it's still up and going. We've kind of been taking our time to make sure we've got our ducks in a row because we really wanted to be mindful of addressing both the psychosocial as well as some of the non-adherence issues recognizing that some psychosocial difficulties can make liver management that much more challenging for families. Compared to previous visits with me being integrated into the clinic, there's an opportunity for me to administer screeners to families to allow for some of the early identification of those risk factors with routine assessment. A lot of these families aren't presenting with glaring fires in which anyone walking in would know that they may struggle with adherence. A lot of these are really sub-clinical. So, with routine assessments, I'm able to get a handle on some of these smaller things before they kind of get larger and really start to impact their disease management. It also allows me to intervene at the point of care. Perhaps not surprisingly, families who are struggling with adherence issues by making a referral once there's a concern that's been identified, it does require an additional clinic visit or scheduling and if they're non-adherent to something as important as their immunosuppressant medication or they're inconsistent with getting labs, it's no always likely that they're going to follow through with their referral to a psychologist outside of the clinic. By being in there and capitalizing on them being motivated right then and there, I'm able to kind of be a little bit more effective during that clinic visit.

Michael: Do you think this is a trend, Dr. Ryan, then? Having a psychologist really a part of the transplant team? Are we seeing that in more community hospitals, smaller hospitals? If not, is that maybe one of the goals you have?

Dr. Ryan: I think at least for Children's Mercy it's becoming a theme definitely. The assessment of non-adherence and general psychosocial functioning is becoming more prevalent across institutions, I think, but I'm not sure that we're as integrated in terms of having a psychologist ready, in clinics the day of in order to intervene and provide families with additional resources. While I think there is more regular assessment during clinics, a lot of times it's still based off of referral in which psychology is involved.

Michael: Well, Dr. Ryan, it sounds like an exciting program and I know that the outcome is going to be very positive for you so I wish you the best of luck in developing the Liver Medication Adherence Program at Children's Mercy Kansas City. Thanks for coming on the show. You're listening to *Transformational Pediatrics* with Children's Mercy Kansas City. For more information you can go to childrensmercy.org. That's childrensmercy.org. I'm Dr. Michael Smith. Thanks for listening.