NASPGHAN Transitions of Care – Transcript

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Right, we can get started. Good evening and welcome to our Transition of Care symposium today. Thank you for being here. We know you could have been many other places this evening, but we'll try to make it up for your time and good food. I'll start with some introductions, so I am Doctor Neha Santucci. I'm an associate professor at Cincinnati Children's Hospital, and I'm the director of the Disorders of Gut Brain Interaction program, so I'm a pediatric gastroenterologist. And I'm Kristina Skarbinski, and I have been a nurse practitioner for 11 years.

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I work at Mass General Hospital. You might hear my Boston accent. It's OK, I have many hats. I split my time between the foregut surgery program and the neuro intestinal health GI program. And I also have helped develop a transition of care for patients who have been diagnosed with autism spectrum disorder. And I'm Joy Liu. I am an adult gastroenterologist at Northwestern. I've been in practice for about two years and I have a focus in neurogastroenterology and motility. I see patients with gastroparesis, refractory constipation, IBS and I work with our partners at Lurie Children's Hospital in our care pathway.

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So just a few housekeeping points. There will be a video recording of this meeting. Please turn off or silence all your devices and please refrain from checking your e-mail during the meeting. I know that's difficult. There will be a Q&A session at the end of the meeting. So there are some index cards provided on each table, if you want to fill in, they can pass them along to us and we can read them out or we will also have mics that can be passed around so we have more of an audience engagement. And then we also have a post meeting survey at the table.

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Please complete that at the end of the presentation. These are some disclaimers and disclosures. And then the objectives of today's session are to review the diagnosis and management of functional constipation and
overlapping symptoms in chronic idiopathic Constipation. Understand the importance of a seamless transition of care and its impact on patient outcomes. Discern the barriers that interfere with this transition from pediatric to adult care, and finally discuss a multidisciplinary approach to improve continuity of care.

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Before I get started with a show of hands, we would like to hear who here has a very well developed transition of care program or has a good transition system for their pediatric patients to adult care. OK, we have some hands, very handful, but that's exactly why we are doing this conversation and talking about this today.

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So let's start with some differences between pediatric and adult Constipation. So functional Constipation is a common disorder in all pediatric age groups. It is estimated to prevail up to 30% worldwide. It accounts for 10% of general pediatric outpatient visits and up to 25% of pediatric gastroenterology visits. So very common problem. It occurs in all pediatric age groups, from newborns to young adults. Constipation starts in the first year of life in approximately 50% of children.

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So we use the Rome IV criteria to diagnose functional Constipation based on these five patient reported symptoms, the first being infrequent defecation less than or equal to two bowel movements per week, fecal incontinence, having at least one episode per week, stool withholding behavior, painful defecation, hard or large diameter stools that can sometimes clog up the toilet. I've not mentioned the physical exam criteria, which is sometimes feeling a hard mass in the rectum which suggests impaction. And here is the Bristol Stool scale that we have divided for pediatric patients, from type one to seven, which I'm sure we all use in our practice and our teenagers love listening about that. But moving on, pediatric functional Constipation has multiple biopsychosocial factors affecting it.

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I'll read through these starting with psychosocial factors. Major life events trauma which can be medical trauma in the form of use of excessive enemas and rectal therapy, abuse, socioeconomic status, education level, parent child attitudes and very importantly school related factors where they might not be allowed to use the bathroom, in school, during school hours, or they might not like to use the bathroom because their peers might ridicule them. Physiologic events or behavioral events, which could be conditions such as attention, attention deficit hyperactivity disorder, autism spectrum disorder, anxiety, and other psychosocial disorders, very commonly toilet training and behavioral issues around toilet training leading to stool withholding behavior.

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Physiological factors which are a little bit less common, include colonic dysmotility, the more common one being impaired anorectal function. Other genetic disorders, bile acid related issues, gut microbiota affecting this ideology and structural abnormalities. And then the last but not the least lifestyle, the amount of diet, fiber in the diet, fluid intake, obesity, physical activity and sleep health.

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I'm curious, how would that factor in adults with chronic constipation? We should be taking very similar factors into consideration. There are some similar biopsychosocial factors that we evaluate our adult patients for. Importantly, psychosocial factors similar to what Doctor Santucci mentioned. There are external stressors, although unlike in the pediatric population, our adult patients may deal with having to use the bathroom at work, having bathrooms with shared stalls, anxiety around having bowel movements, depression, and other kinds of issues with toileting behaviors, in general. There are also physiological factors such as dyssynergia, which we evaluate with anorectal manometry, delayed colonic transit, theories about mucosal and immune function, and the role of the gut microbiota remains, you know, an area of active research and lastly, we consider neurologic factors that contribute to symptom severity such as visceral hypersensitivity, the role of gut brain interaction, a sensory and motor function, and central nervous system processing.

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I think the big thing here is to remember that children become adults and you know especially patients with autism spectrum disorder, they become adults just like all of us. And so a lot of times you have to think about what else is going on in including stressors, anxiety, toileting behaviors. A lot of times I have to think about those and really hone in on those questions when they transition into an adult GI practice. And a large number of pediatric patients grow up as adults to continue to have constipation, which is as high as 1/4 to 1/3 of those patients.

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The ESPGHAN and NASPGHAN guidelines for children with functional Constipation which was developed in 2014 and is, I know there's a new iteration coming up, but we're going to discuss these for

now as these are the published ones. Do not recommend high amount or excessive amount of fiber as a treatment of pediatric FC, but we do say normal amount of fiber is recommended for children according to their age as specified. The next part is looking at behavioral and physical interventions.

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Encouraging relaxed posturing by providing food support during bowel movements, reinforcing positive behavior potentially with incentives for passing stools. Pelvic physical therapy may help improve constipation and fecal incontinence. Instrument based techniques such as biofeedback may help promote regular bowel movements. And then looking at behavioral and psychological interventions, behavioral health services should be utilized for children and young adults with behavioral problems to center these around toilet refusal, stress, fear of defecation. Psychological interventions can facilitate the use of relaxation strategies and adaptive thinking in children and adults to reduce symptom burden. Actually one of the studies we had published was centered around self-efficacy for functional constipation, meaning how well a child thinks that they can poop actually affects their outcomes with constipation.

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I really want to hone in on that with when you're taking care of patients that are transitioning from pediatrics to adult taking a proper history is so important. What caused the anxiety to bring them to fear that bowel movement so much? Was it the pain? Was it seeing blood in the water? Was it certain environmental stressors that occur around defecation? So really just making sure to hone in on those things and then trying to find interventions to reverse some of those.

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And to add to that, we're discussing the role of medical trauma. It's actually rectal therapy and I have 60 and 70 year old patients who can vividly recount being chased around their house with an enema and here we are discussing refractory constipation all that while later, it really does factor in. I think that becomes very important, especially in that zero to four years of age before they have the cognitive ability to understand that it's OK to sit on the toilet and what it's meant for. I think we need to be very mindful of the therapies we are using in our patients when we send them to the emergency room, when we think that one episode is not going to make a difference, but it actually does.

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Let's talk about what the guidelines actually mention. The ESPGHAN and NASPGHAN guidelines divide the principles of pharmacologic management into 3 categories. 1 is disimpaction. This is recommended prior to initiation of maintenance and these are the agents that are commonly implied for disimpaction which might actually be different in the adult population and we can talk about that more on the next slide. The second phase is maintenance recommended to prevent re accumulation of feces. Treatment effects should be evaluated after one to two weeks. Treatment should continue for about 2 months. In the pediatric world, a little bit longer, I would say. Symptoms should be resolved for greater than or equal to one month. Pharmacologic options in the maintenance stage include laxatives.

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These can be polyethylene glycol, Lactulose, magnesium hydroxide, stool softeners and then other prescription agents. And the third phase consists of weaning where 50% of children with functional constipation on maintenance can discontinue treatment 6 to 12 months after initiation. And this is quite important to hold on. And most patients take medicines as needed. While that might not be the best approach because this problem can continue going on. But I think these are important things to talk to our patients when we discuss management because these can all affect treatment outcomes. Weaning can be considered if frequency of defecation is more than three times per week and maintenance should be gradually reduced to prevent relapse. Would you guys want to add anything that you would do in adult patients?

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A lot of times when patients transition into adult GI, even if they didn't change the transition from pediatrics to adult, there's always this fear of chronic laxative use and how do we mitigate that? How do we have them feel more comfortable? One of the approaches that I have started to bring up is if you were to come in and you were to have high blood pressure, would you expect to take that blood pressure medication once and that blood pressure would be resolved? Or do you think that this is a chronic issue that you have to take the medication for and it's the same kind of situation with laxatives and constipation. And as long as you're being monitored and you're watching out for alarm signs and you have somebody in your corner in the healthcare field, I think we can make sure that you have a smoother transition into getting to the results that you need to go to the bathroom.

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So you'll see here there's multiple options for adults and then there's limited options, I think for pediatrics. For adults, you know, once they come in to see me, I have more options obviously with some limitations with insurance, financial access to certain medications, but a lot of times I feel almost blessed a little bit because I can have more options to take care of patients. And a lot of times what happens though is they've already tried those over the counter things you walk into a CVS and I try to I sound like a dork here, but I sometimes will go into a pharmacy and just see what's out there, what's easily available you could take off the shelf.

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And by that time I know, OK, this is what I know the patients already tried those over the counter mechanisms. Now when do we transition into a more prescription approach? Yeah, so that's interesting and some of the choices are determined by just patient preference. Some of the choices are unfortunately limited by insurance approval. As I think everybody in the crowd can attest to, there are many drugs we would like to use, but our patients are actually better off when they turn 18, when they are 17 years and 364 days, they will be denied the treatment, but they turn 18 and they will get the same treatment. That's the unfortunate reality.

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I see what you mean by that change, which you know, is not a huge change in their age, but a huge change in their healthcare availability and access. So for pediatric patients the most common osmotic laxatives that have been recommended as first line therapy include polyethylene glycol and lactulose. Magnesium hydroxide, bisacodyl and senna have been recommended as additional or second line treatment. We actually use more stimulant laxatives then you would expect in the adult GI scenario, we're OK with stimulant.

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Oftentimes in my practice, I base what I'm going to give the patient on the history that they're presenting to me. If they're saying I have that urge every day to go to the bathroom and I can't get it out or I am able to get it out but I'm not feeling completely evacuated. That might be some reason for me to use a stimulant laxative. But then if they're telling me I can't go to the bathroom for three plus days, I have 0 urge, then I'll start to use things like the polyethylene glycol.

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I don't use Lactulose as much. I'll be honest about that and magnesium Hydroxide, believe it or not, I actually have more patients coming in with magnesium oxide on board. Just to add to that, I've started to use magnesium more in my practice. It does get to a point that you raised earlier about the concerns about safety of some of these medications. Many of my young patients come in concerned that they might get tolerant or they might get dependent they're worried about chemicals in the medications and we spend a lot of time talking about the safety profiles.

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We use polyethylene glycol primarily in my practice and then we have used Senna if they need a second line agent as a stimulant. Lactulose and senna might be good alternatives when your patients are very concerned about polyethylene glycol because they can be considered more as natural medications. Lactulose comes from, you know, a sugar and natural sugar and senna is a natural plant derivative. So sometimes when you need that buy in, these could be your alternatives in the pediatric world.

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This is just for everyone's information. Linaclotide, there's a new indication for pediatrics, but you can read this and find this available to you if you want to read more into it.

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So as you can see, there are some other options that adults utilize. A lot of times for my practice I use secretagogues a lot, especially if I'm thinking that there's a more transit related issue with their constipation. Linaclotide is generally my first line. I like the fact that there's multiple options now to treat in the adult population.

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It's important that when you start these medications, you time the doses or take them as appropriately as you can. So a lot of times educating the patient to take it before a meal is important. Lubiprostone is another option that I'll use as well and often times it's my second line although sometimes I use cannot hide depending on insurance barriers that might come about. But lubiprostone is the BID medication. It comes as 8 micrograms twice a day or 24 twice a day.

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The adult population plecanatide is another one. It's 3 milligrams once a day. You don't have to worry about timing to meals. And prucalopride, often utilized for bowel movements, but also if the patient has some delayed gastric emptying as well. You can kind of kill two birds with one stone.

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One point with the sort of wealth of options that we have on the adult side is that sometimes patients feel as though we are doing trial and error, which to a certain extent we are. If they're not responding to one agent, we maybe try our second favorite one, then our third favorite one and I typically set at least two weeks of a trial.

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And so I try to set expectations with them when prescribing. And also tell them that it can be a long process to find the one that works best for them. So secretagogues that is lubiprostone, linaclotide, plecanatide, they are guanylyl cyclase agonist. And the pediatric studies are there, but they're very different. The data is kind of varied. So lubiprostone showed great efficacy in an open labeled study, but in the double-blind placebo-controlled trial it was not superior to placebo. Linaclotide with the recent trial that came out showed improvements compared to placebo in spontaneous bowel movements per week and it became the first FDA approved medication for the treatment of functional constipation in pediatric patients ages 6 to 17 years of age.

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And then prucalopride has shown again mixed effects in clinical trials in pediatric patients we did it has shown. Some efficacy in other small studies and what we find is the it's a 5 HD 4 agonist. So it might be really superior or good in patients who have Constipation and have upper GI symptoms. It stimulates the entire GI tract. So a study from our cohort, we showed improvements in upper GI symptoms, we

showed improvements in esophageal dismotility so that might be a consideration when you want to, you know, minimize excessive medication use. You could use one medication instead of three different medications. I tried to tell my patients too, GI is like a conveyor belt. So if you can get things moving, sometimes other things or other GI symptoms can improve as well. Yes, that's a fair. That's a great point because if you have traffic jam below, things will be stuck above.

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So how many here have an APP that they work with in their practice or are an APP? Wow. OK. All right. So key roles of the APP or the advanced practice provider, which includes the nurse practitioner or physician assistant, includes managing patients throughout their journey from diagnosis to treatment. Oftentimes, I see patients several times in between the physician visits and I'm there to provide education and reassurance to help them stay the course, guide them through everything that they're dealing with symptom wise and I'll talk a little bit more about that later on and how I do that but also ensuring collaboration between physicians.

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So again, I talked to initially about my role as somebody who works between a surgical side and the motility, GI side, making sure that communication is there because there's nothing worse than being a patient and feeling like your providers are not talking to each other. So this is where I think the APP can really facilitate that discussion and then act as advocates for the patient and family. So if you look at this slide here, there's a lot of people listed on here and I think it really takes a village to take care of a patient. I'm very blessed in my practice. I have the assistance of a patient advocate, it's actually in our facility it’s an occupational therapist who can help with making sure that the patient can come to visit. So I've had patients with autism spectrum disorder, they don't even want to come into the facility because they're so traumatized by everything they've dealt with throughout their healthcare journey. And so making sure that any fears are mitigated or improved, such as maybe a quieter environment, things like that, it's really helpful to have that. Now I understand we all can't have that, but we can all do our part in maybe making a transition into GI adult less stressful.

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For anyone who's coming into our practice, and so we have the option of utilizing nurse specialists, we have the surgeons there to talk to, dieticians, the gastroenterologist, both on the pediatric and the adult side and then child life specialists. We forget that I think in the adult world because we don't utilize them as much. But when I was a Pedi nurse back in the day, child life was so important. And then just somebody to help with that transition. So your administrative support to say Hey, do we have all your records etc? And just to add to that, so transition of care was not something we talked about until the last year or two, but it has become and everybody has noticed that this is a very key important issue or a barrier that we are having in effective care of our patients. So this year we had two papers that came out. One was the ANMS, which is the American Neuro Gastro and Motility Society, and ESNM which is the European counterpart wrote a position paper together to give some guidelines on how we could how during transition of care for patients with neurogastroenterology and motility disorders.

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And then we as part of the NASPGHAN Neurogastroenterology and Motility Committee, wrote an urgent statement in JPGN and as an invited topic of the month, again addressing the needs, the problems and what can be, what should be, what are the future considerations we should think about to solve this problem, so most of our slides are going to go through some of those papers.

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We'll start off with our patient case. So this is DJ, it's our patient is a 19 year old male. He was suspected to have functional Constipation at the age of 9 by his pediatrician. His Constipation started at the age of seven and he had significant abdominal pain that often caused him to miss school. And so there was anxiety surrounding bowel movements and he was referred to a behavioral therapist. He had some

coping strategies such as breathing techniques, proper toileting behaviors, in addition to using polyethylene glycol. And it helped us improve, have helped to improve his symptoms, but only about 80%. And he felt that there was still some room for progress. So his transition to adulthood. By the age of 17, he stopped taking the polyethylene glycol because he didn't like the taste and this made his symptoms just worse. And so when he turned 18, he was scheduled for his first appointment with an adult GI specialist. But he didn't attend because he felt very overwhelmed and nervous by that transition that he was already doing in his own life to college, adjusting to that environment, etc, and also leaving his family.

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So after moving, he struggled to prioritize his health care and he didn't actually continue facilitating the, you know, going to his own appointments etc. So at this point he's settled into his college life. He's now experiencing increased abdominal bloating, less frequent bowel movements and an average Bristol school stool scale of two. So these symptoms have become a concern for him. He's noticed that he's having a lot of changes in his diet, his stress levels are going up and in his routine is just being affected significantly. He reached out to his primary pediatrician. He said that he should try polyethylene glycol, but DJ was hesitant again because in the past he didn't really like the taste. He also didn't feel like it really provided much benefit, and he possibly felt that the bloating was worse when he did take it so he asked his pediatrician for a referral to adult GI specialist and when he reached out like anybody here is surprised there was a nine month wait for consults. He's becoming increasingly frustrated by the process. He feels unsupported, without any resources and he's just upset. So what actually went wrong with his transition of care? I'm going to ask my colleagues here.

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So often when I see a patient like this in the adult clinic who's establishing with an adult gastroenterologist for the first time, one of the first sentences that they say is it took so long to see you. When I say and now we have to figure out everything, often these patients don't come with records. I might get lucky and see something in care everywhere in Epic, but especially when coming from the community. Those records may not be available unless the patient knows to prepare those ahead of time and they should be counseled. That you know, it's helpful to bring paper copies of your records to the first appointment. A lot of times they may feel as though they had a certain cadence and a certain manner of care with their pediatric gastroenterologist, and that may be different once they're on the adult side having had counseling on how it might be different when transitioning to a new provider would be helpful.

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Yeah. And then let me tell you, this is such a real world scenario happening. We see this all the time. I feel like the patient comes, they're lost to follow up. So what I thought went wrong here was one. I think the patient just got lost in the system because things were OK and then they came when they were things were. Not really, OK. We really don't know what happened in that intermittent phase. I didn't see any transition readiness, any transition planning happening potentially because we lost the patient to follow up. There was no serial visits that were discussing transition of care and there was no handoff to the adult provider and that is so real too. When they reach teenage years, it's virtually so hard to have any of my patients take polyethylene glycol because they are done with it. They are fed up. You can convince them up to 12 or 13, but past that they will always ask can I get a pill to get this.

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So I think there's a lot of changes that are happening in this age which you don't have these conversations with your patients, you will miss to effectively transition them. The second big point that happened was to notice that he was overwhelmed by going to college because transition is not just from healthcare, it's also a transition from their way of life. So they're dealing with a lot at that crucial stage, there's a lot of changes happening physiologically, behaviorally and physically in addition to their

medical changes. So I think we need to be wary about all those factors as well. And how many of you have heard a patient say, I don't want to talk about my bowel pattern? I hear it all the time and how I try to, you know, lighten the situations and I say I talk about it all day long, so you might as well come and talk to me about it. I'm used to it at this point and then they kind of relax a little bit.

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When a patient is leaving their home, that's a very stressful part of their lives a lot of times when they transition to adult care and I see them, they're the ones telling me that they when they go out and they leave their home, they're looking for the nearest bathroom, no matter where they are. OK, I know that if I go to the store. The bathrooms on the left hand side, I know where to find it, etc. So, you know, they have a lot of different stressors that they're just, you know, it's just compounds over time and really kind of hone in on that during your discussion of transition of care.

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So I think that's one of the things that we could do in addition to starting that discussion early because of that discussion is going to be an ongoing discussion, especially we're all busy clinicians. Our practices are booking out several months in advance and that's kind of where we are at that point, but having the early discussion, having a plan in place knowing where that patient's going to go when they do eventually transfer to GI adult could really make things easier if we communicate within the different divisions.

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All right. So moving on to how is transition of care models going to look like. So there are differences in pediatric and adult care model. The pediatric care model caregiver plays the key role in patient care. They are the ones who are present for most or all visits. They have access to health information and test results. They are the ones who helped provide the medical and medication history, answer questions and are involved in making care choices. So there's, as we all say as pediatricians, we don't just treat the patient, we treat the family. So they have a huge role that they're playing in all aspects of their medical care. Meanwhile, in an adult care model, we are really prioritizing the ethical principle of autonomy. So last point here, but we expect our patients to be making decisions for themselves based on their own interests and priorities as long as they're capable of doing so. And so the ways that it's demonstrated is that the patient is usually attending their visit either alone or indicating that any other people present at the appointment are people that they have invited to be there, not somebody who has basically demanded to join the appointment. We treat their health information as private and would not share it with other family members or significant others unless the patient themselves provides that permission and we direct all questions to the patient if they're able to answer those questions. We want to know how are you as the individual feeling. I do have younger patients who still have their parents present at their first visit. If the parents continue to come for all of the follow up visits too, I regard that with a little bit of weariness. And then I do have older patients who still have their parents come, you know maybe 50 year olds whose parents are still coming with them to the visit.

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And that's the sort of situation but typically we are looking to the patients themselves to provide answers and make decisions about their health. Yeah, I think this is the spectrum that you know, each patient is going to transition differently between the pediatric and the adult care model and there still might be some leftover pediatric care model into our adult care model as. Doctor Liu mentioned, patients do like to come with their parent or their sibling or their caregiver. My patients with autism spectrum disorder will come with their group home member, their nurse, their family members or sometimes just the group home and I have to rely on their history because they're advocates for the patient when they maybe cannot communicate what their needs are. But I think it's important that we kind of take things as a case by case basis. I think when a patient is transitioning from pediatric to adult and they start to say, well, can you talk to my mom about my problem, I often have to be that person to say I'm happy to have your mom on speakerphone with us and to provide some support, but I really think it's important because this

is about you and what you're experiencing, that I hear exactly what you're feeling and that you're able to kind of communicate that with me.

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It's so important that you're the one who's the primary speaker and then we allow the caregiver or the parent to speak as well. And it takes time, but eventually I think they're able to, transition into being their own advocate over time. And that's two important points here. One, it's already so difficult this system. Transition is hard, but patients who have neurodiverse spectrums, it becomes even harder to transition in this model and I'm curious to hear what other things you do in your subsequent slides as we talk through. And then the second point was what you said, Kristina, was the autonomy that the child or the teenager should be having. I don't think that's going to magically start at age 18 and not at age 17. I think that's where I know it might be uncomfortable to us as pediatric gastroenterologists and we want to build that amazing connection we have grown with these patients where we might have to start between the ages or the years of transitioning. Start developing those practices and habits so that transition becomes easier and we'll talk a little bit more as we go on through these slides.

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So transition of care, we've been talking about this for some time now, but it's defined as the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child centered to adult oriented healthcare systems. In 25% of children with functional Constipation, symptoms persist into adulthood, so long term follow-up studies suggest that symptoms may persist for many years. Outcome data for patients with persistent Constipation into adulthood is lacking. In some terms, persistence of symptoms may lead to lower quality of life and poor clinical outcomes at adult age are usually correlated with three baseline clinical characteristics. If they present with an older age at onset, if there's a longer delay between the onset of symptoms and the first clinic visit which is key because patients may not get referred from their primary care provider to a pediatric sub specialist and that might be a part. So it's not just a problem with the pediatric GI system, it's the problem has to be dealt with at the primary care level as well.

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How we have seen multiple times patients come to us and it had been, it has been told to them that it is OK if you do not poop less than two and this problem is going to eventually outgrow. I think that's a huge point to be wary of that this delay can be really harmful in the long run. And then third is low defecation frequency at baseline. So the number of bowel movements they have can directly correlate with how or how severe their constipation pattern is into the persistence of symptoms in adulthood.

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So when considering the transition of care, when I'm seeing these patients in adult clinic, I see patients generally at the age of 18 or older, very rarely the occasional 16 or 17 year old in general from my patients between 18 and 21 years old of age. I like to consider any psychosocial factors that may be contributing to severity of symptoms or GI related anxiety that we discussed during their visit. Like has been mentioned, transitions away from home, going to college, maybe starting a new job, different relationships, even different relationships with their parents, even if they're still living at home. Some of the additional challenges that may complicate treatment of their symptoms are complex medical conditions, developmental or intellectual disabilities, or underlying mental or behavioral health conditions. We know that a delayed transition leads to worse outcomes overtime. So even though patients and their families may feel more comfortable continuing with the pediatric clinician past the age of 18, we really want to emphasize that the sooner they can come over to the adult clinic in a calm and controlled way, the better off they will be in the long term.

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And just to add to that, there are studies in chronic pain conditions that transitions after 21 years or delayed transition can actually lead to worse outcomes and patients themselves feel that they are not

prepared. They feel like they found the transition of care process very confusing and that led to more bounces in the emergency room and the other in utilizing more healthcare resources. So we don't have excellent data in our patients, but I think, I suspect it applies the same way to our neurogastroenterology and motility patients too.

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So just to expand upon that a little bit, some of the repercussions due lack of transition of care might include a disruption in continuity of care. So one of the things that might have emerged from the case is that the patient went from having a pediatric GI that they knew and trusted to having nobody for a period of time and wait times of nine to 12 months for a new adult GI visit are not uncommon. And so having that gap certainly would ramp up the anxiety for any patient. It would be better to have a visit with a new GI before there were problems to establish that care so that when problems would come up, it could be a quick message through the portal or it could be a quick follow up visit instead of having to establish care with an adult provider when the when the patient is in distress. There are certain psychosocial challenges you know that we discussed before that may be contributing to symptoms overall. One particular point here with the social piece is the change in insurance that occurs when patients are turning 26.

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And so this is something that patients may feel prepared to navigate on their own, but other patients may not and depending on their work status or their financial status may not have that many options. So we do always want to figure out when do we need to have a social worker formally involved to support them? Like what is their family support? And then the last piece is how does all of this affect their compliance? Somebody who's not in regular care may not be very compliant with prior treatment recommendations. That may lead to worsening symptoms as well.

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So I'd like to ask my colleagues, what are some of the goals for a successful transition of care? Yes. So I think what I find is a bringing up transition really early so patients are not overwhelmed. It is not fair to them if they come to a visit one fine day when they are 18. Now we're going to transition care when they're hearing it for the first time, it's going to raise alarm bells. It's not going to be a fun process. So anticipating that at 16 to 17, bringing up questions about like we're going to transition. Usually we say if you see our paper, we actually talked about 12 to 14 as the age to 1st bring it up that we're going to transition you. I can totally see the expression on the teenager and the patients face when they come to see you at 13 and you say, OK, we're going to talk about transition. So sometimes it might not be realistic, but I think that's the point where we can start talking about transition readiness.

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Are your patients ready for transition? How can we make them ready for transition? So I think discussing transition readiness. Second is transition planning. So talking about this in that one year before they are transitioning, really finding out their goals, where are they going to go? Are they going to be in the same city? And it's quite important to know where they're going to go for college because if I transition them to someone in the same city they have been going and they are going to eventually end up being five hours away in another state for college.

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I don't think we did this in the correct fashion. So I think understanding what their transition in life is going to look like 2 is also making sure not transitioning them like in the case when they are actually going through a flare or they're having worse symptoms, that's even harder because now they're really struggling and then we want them to see somebody unknown and that might again, not be very pleasant. Instead, when they're actually at a good place, meeting with them, having that follow up where it's the follow up is really essentially you're doing great. This is a perfect time. The transition you over might

really help them feel really supported. They might be more open to the transition and it might go more seamlessly. It gives the adult providers a chance to know their patients too. When they are at a stable stage. It's harder for you guys, I think when they're coming to you really in a worse state, just your wait times are so long getting them in quickly becomes harder. So I think just everything, planning things perfectly in an in a perfect world will help that transition.

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So usually involving social workers might be a great way to do that. And then finally, I think an effective handoff is really important between the pediatric and the adult providers. Some of these patients that we see are very complex. They've had long charts, long histories. I think it's unfair on the adult provider to have to sit and figure this out or they might do some things that have already been done. And those charts are really hard to read if they haven't been summarized or in complex patients simply. So either having like a nice e-mail one to one summary or having a phone call to these patients to the provider might really make this whole process easy for all of us.

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I think you hit on a lot of points there, but early discussion is really the key part of the puzzle here. If you really look at it, your pediatric patient has seen this provider, the pediatric gastroenterologist, the primary care for their entire lives. They've developed a relationship. They feel comfortable with them. They feel that they've already given them all their most intimate issues that they've had and now they're transitioning to someone that they don't have a relationship with. So maybe if your facility allows it, developing a one time visit where both the pediatric and the adult GI are in the same either Zoom meeting or maybe the pediatric, yeah, I've had a situation where a patient was coming over to adult clinic and the pediatric GI came over and said, alright, I'm going to pop my head in real quick and just say, you know, oh, yeah, I agree with this or anything to kind of help that transition to become smoother but also feel like the patient.

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Have the patient feel like, OK, they're really thinking about me, they're talking about me, they're trying to really put their heads together to make sure that I feel comfortable. Another thing is, is if a patient is going to be away at college, figuring that out, I agree is totally important prior to just finding them a GI and saying, oh, this is the one that I refer to. There you go. Where are you going to college? Are you even going to be able to get to that gastroenterologist? And if you can't, where can we find somebody that is close to you so that you can actually make those appointments? Or if they're in the same state with telehealth, are you going to be able to maybe hop on a Zoom call in between while you're away at school to update on your symptoms to the adult provider. So those kinds of things should be discussed, anxiety related to transitioning care discussed that or discuss what are you worried about you or what's going to happen because a lot of times they know that when you transition to adult there are a lot of different tests that we might start putting them through and that's even for me if I go to a doctor's appointment and they're saying, oh, yeah, I need you to do A,B,C. And I mean, no one's excited about going through tests, especially if there's different types of tests with different needs. So and then if a patient's coming in with any neurodiverse diagnosis, they have that patient advocate on board early and any needs are implemented early through that patient advocate.

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So and again, don't transition when they're going through a flare because that's also adding to the stressors, the burden and the urgency and it just makes it to be very, very challenging in the long run. And then as we said, it becomes really hard sometimes because we have seen this happen where they will go to the adult care provider. They've done it, we've done it, We've sent them, we've said our goodbyes, but they had an experience and they are right back. Or if we are like, no, no, we can't take you back, you're gone, right? Where are they going to go? Emergency room, hospitals find ways back in. So we actually might be promoting in that situation. They might be promoting a lot of more Over medicalization, over utilization of healthcare resources. So I think paying attention to that where some

of this is discussed with them, some of this, I don't think our responsibility as pediatric gastroenterologist ends the minute we have sent them away. It really goes once they have established a relationship with their adult provider.

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So there might be that transition phase, which might not be a day or two, it might be 6 months or so where I think we might have to do some effective hand holding, but give them back to that. It's just like going to preschool or kindergarten, my friend. Well, as adult gastroenterologist, it's our job to make sure we know our patients right before they come into a visit. We have all those records. We look ahead, we maybe do some pre thinking before they come into a visit that's really important. And then also that consult visit if we can, trying to give them enough time to chat with us and really make a just develop a rapport with them.

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So I think those are all important. So then set expectations for skills needed for a successful transition. Before meeting with the patient, consider the following skill sets needed for transition, their understanding of the diagnosis, their knowledge of the medical system, their acceptance of the diagnosis, and their willingness to establish a healthy and supportive patient healthcare provider relationship.

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What are some of the common barriers that you, as audience, frequently observe in the transition process? We'd love to hear from you. You can just raise your hand and I think we can bring mics around if needed.

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From the beginning. The wait time, if you want to refer to energy, I think when they come back in six months, it will just interfere, interrupt the care. Yeah, I think someone next to you had a comment too. I see a lot of reluctance to leave the pediatric practice, and I specialize in short bowel syndrome transition of care, but we don't have adult GI providers to send them to. Yeah. And Doctor Steven, you do transition of care models for intestinal rehab, so we'd love to hear. Yeah. We focus on education, transition readiness assessments, and we built A1. Their curriculum teaching them like what is their condition? And we're surprised that these children that have had this diagnosis since birth at age 16/18/20 don't know what short bowel syndrome is. They don't know why they take all these medications. And they're not going to be compliant if they don't understand why they need to take all of these things. Yeah. But we're having a big issue with the transfer part, but it's a process and it starts at age 12 having those discussions.

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Parental anxiety about backing off. Excellent talk. FYI guys, I think for me. Since maybe I babied them a little too much, but then they don’t want to go to adult care. They're not as I don't want to say the word coddled. But in essence, it's a little bit of that, I guess in the adult world. They don't. Yeah, I think that in nutshell, I don't know how. Yeah, it's a scary transition. Absolutely. All good and valid points. Anybody else? OK. Thanks everyone.

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So. As we talk about transition of care process, we really have to understand the key stakeholders and there's so many, I said before it takes a village because it really, really, does. And I think it does even in GI, no matter if you're even transitioning into care it this deep list of key stakeholders are intended to be part of the. Process for as long as possible and probably for the entire span of their lives or their GI

illness. So the insurance provider we all know that is a big, big heavy hitter there. Pharmacy, the primary care provider. I think as sub specialists, sometimes we really forget about the primary care and we don't mean to do it. But they are so important and so critical for the patient to make sure that they continue to keep on top of their treatment plans with their sub specialists, adult gastroenterologists, the nurse that might my nurses, my right hand, she is the one that speaks to my patient in between visits, gets intermittent history and then converses with myself and other key players in their in their GI team to make sure that any interventions in between are smooth.

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Dietician is important, occupational therapist we talked about that that's the person that I utilized to make sure that there's some advocacy or a patient advocate is the other name for it. Social worker so important all the time. It can help with a lot of different things psychosocial, financial, etc. needs and then the pediatric team again, primary care provider that pediatric gastroenterologist, the nurse, the dietitian so similar things, but then also the child life specialists and the psychologist, I wouldn't even say the psychologists on the GI side of the adult GI side of things. We, in my practice, couldn't do our work without them because there's so many pieces to the GI tract that are not just GI. You have a whole brain gut interaction and then that transition coordinator, that's where our admins, our secretaries are really the front lines for us to making sure that any needs are facilitated appropriately.

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So I was going to add something here. So one thing you mentioned was nurses. They are such key providers. My nurses are in the audience here and they do most of the heavy lifting for us. If they can convince the patients to go, the patients will go. If they cannot convince them, they won't. So I think that just utilizing all the players that are involved in the healthcare system becomes important. They'll be your best allies to make this. And then there can be different models, right? There is a pediatric GI that's operating in a private care model that's transitioning to an adult GI. There can be a pediatric GI operating in a tertiary care with the GI psychologist where they get all these dietitian psychologists, child life, social worker, pediatric GI, then going to an adult GI who does not have those components. There can be a primary care provider transitioning to an adult GI, which is rare. But the other way round where you might be a pediatric GI and they have all these rich advocates going to just a primary care provider because the state they go to they do not have these other axes.

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I think there might be many different trajectories and that might make a huge impact on how they are getting transitioned as well. And I think the main thing we have to remember the patient is the number one key stakeholder. I don't want to, forget that the patient, the family, where they work, where they go to school. All of those things can interfere or help with their care process.

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All right, let's talk about some barriers to transition of care like you all mentioned from the pediatric expert, lack of a repository for adult care providers sometimes as neuro gastroenterologists. One of the biggest barriers is I do not have a counterpart neuro gastroenterologist in my city or my state. Who do I transition to? Do I even know all the adult neuro gastro providers or do I know all the adult pediatric gastro or the adult gastroenterology providers? We don't have that data readily available in one snapshot unfortunately yet there's a gap in consultation with the adult providers and there's lack of mutually agreed treatment guidelines between pediatric and adult. Their providers, as you saw, the medications are different, approaches are different. I think we just need to be communicating more or coming together more and talking more about that to address some of these barriers.

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On the adult side, kind of to the point our audience raised, I find that when I ask patients coming to see me for the first time what they understand about their condition, they may or may not be able to, you know, tell me what their diagnosis is and why they agree with that diagnosis. Some patients come in thinking that they have a different diagnosis or that they didn't necessarily ever believe that they have the diagnosis their pediatric provider gave them. We've discussed that there is often inadequate medical history available and that's just a matter of direct data sharing and communication. From the side of adult GI, we have many administrative constraints, so I'm lucky to be able to set my new and return visits at 30 minutes each. In the community, it's very typical to have 15 minute new appointments for adult GI and so it's difficult to see a new patient who may have a complex medical history and adequately address all issues in that matter of time.

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When patients come to see me, we may see that they are not sort of fully mature or fully self efficacious and being able to advocate for themselves, make decisions on their own without help from other advocates or family members or necessarily care for themselves and then depending on their relationship with their parent or caregiver. It may be a healthy relationship, it may be a relationship of dependency, and ideally we want to see the parent or caregiver providing the patient support but not sort of running the whole show. And then in regard to the patient or the caregiver, sometimes they come in and they still are confused about their what their diagnosis is. And sometimes it's because they've already maybe even seen a couple of people before they've seen us and they've gotten different opinions that can happen. Access to experts with experience. So that can be challenging. They may not have that access. Lack of transitional programs. I mean, everybody here I think has felt that adolescent age sex, race and or ethnicity. So there's multiple factors with that as well as social, economic status, can they afford to get to appointments? Do they have the support in place? Variation in therapies from pediatric to adult care. So it can be challenging. Like I said, when you come into the adult world, there are more options for medications that they may not have even heard about. And then youth and young adults prioritizing their life circumstances over health. So that's common.

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And a lot of times, how do you kind of integrate those together to meet them where they're at, but also have them understand what their diagnosis is and how important it is to actually focus on it and treat it. One thing I have to say is when this access to experts with experience, it might be very challenging, but there are ways that we can help with that. Maybe making our own lists within the clinic that they can refer to. I often do that when I have patients that need pelvic floor physical therapy. I have a whole list of all the different surrounding states. Providers that are specialized in that area that they can choose from to make sure that they actually do and go to those appointments. But also I've noticed too, as in the age of social media, patients are starting to find their own providers and make their own lists. On forums, they're actually putting down OK. So and so does this. Another person does this, they're over here, they are good, yes or no, They have this much experience. There's a lot of different things.

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Transition of care is a gradual process that should be individualized between 12 to 14, identify patients, discuss transition policy, track progress 14 to 18 assess patient skills, develop a transition plan 18 to 26 transfer or initiate that transfer integrate into adult practice. Confirmed transition complete and then patient and caregiver feedback. So the six core elements of healthcare transitions were developed by the American Academy of Pediatrics and can be applied to various transition of care models. In the context of functional Constipation, please share with us what an ideal transition of care process looks like.

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I think for people listening, the ideal process will look different depending on your micro environment. So based on what resources you have and who else is in your area, you may find yourself using a different model. I can say that for myself, my pediatric colleagues and myself have developed a pathway where they know that I'm available. So that's the first step. And the second is that they know that it's,

great to be able to work on transitioning patients when they're relatively stable. If they perceive that a patient is in a flare, they might give me a heads up about the patient, but say we're not quite ready yet. We're going to need a few months and we're going to reach out to you later. But this is just to let you know. A few months before they think that patient is ready to leave their practice, they'll send me a message, often times with the last clinic note and say this is my patient. They can write me a summary if they're want, but it's not absolutely necessary because the clinic notes are very thorough. And they might leave one or two sentences about their sort of critical assessment of the patient. Once they've identified that patient to me, our liaison actually sends the patient a basic packet of information about my clinic. So it includes information about how to register. In our health system, how to call to become a patient at Northwestern, where to get parking, how much the parking is because parking is very expensive. Letting them know that they might, it might take 20 to 30 minutes to walk over to the clinic. There's a lot of sort of concrete information that we provide to them before the 1st visit.

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We generally try to get these patients in within three to six months and then at the time of the first visit we go over some expectations. One of the expectations is that there's a six month sort of. Where they can go back and forth between myself and the pediatric GI. I tell them if you want to go back to see your pediatric GI, that's fine with me. We're in direct communication. Similarly, after our visit today, if I have any questions or concerns, I will reach out to your pediatric GI just to see how these might have been handled in the past. After that six month period, we say the expectation is that you're fully following in my clinic and if there are, additional things that we need to discuss, it should fully go through on the adult side. We hope that helps to minimize the number of sort of desperate visits to the ER that are made or request for inpatient hospitalizations and in my clinic.

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I like to, at the first visit, not change a whole lot. That's something that I tell them. The goal of the first visit is not to completely reinvent the wheel. It's to make sure that you can make it to the clinic. That's very important to us that you know where we physically are located and that we get the chance to now each other a little better. We review your history and make sure it's accurate and we set up follow up appointments. Generally for my patients, I set three month follow up appointments for the first few times. Afterwards, if there is a patient who's a little bit more active, we might be doing follow up once a month. Also at the first visit we'll talk about the TRAQ questionnaire and a little bit more detail later, but I do like to give the TRAQ as part of my clinical assessment.

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Ages 12 to 14, this is really where we should start the discussion. The pediatric expert will work to identify that the readiness of the patient. Are they ready to even start discussing that transition? Review the policy with the patient. One of the things is, is how do we transition patient to any facility? So even primary care to any other sub specialty etc explaining why that transition needs to occur. I am a pediatric gastroenterologist. I have a practice that I see patients up to age ABC and it's important that you transition into the adult GI because of A,B and C reasons and what they can offer etc. And then the adult expert will take that hand off, transition the patient as needed. But also I think at this age just being aware that they're starting that discussion early and are aware of the transition policy that the pediatric expert has started to discuss with the patient and then again the patients skills. How ready are they at that point? Some patients at the ages of 12 and 14 are willing and ready to have those discussions, some aren't. So to establish a transition policy and identify patients, we have to figure out who are ready for those. Really for that transition policy, we have to develop an age range which we're trying to figure out now. And then also, are they able to meet that transition readiness at the age of 18? Are they there, are they able to meet us there or are they at 19 or 20, are they able to understand the privacy and consent changes once they turn 18, which is a huge discussion. And we talked a little bit about that and when patients really don't want to get rid of or I should say be their own advocate right yet and they really encourage they want their parents there or their caregiver there.

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And in the interest of time, I want us to be able to have a Q&A session, so I'm going to go through the rest of the slides a little bit faster. Just hitting the key home points for ages 14 to 18 in the pediatric expert. There's a huge shift happening. Transition readiness, behavioral health assessments, education resource. Preparing the patient and caregiver for the adult approach as we discussed., I think ballpark two big changes that I would talk about are three. One is know their diagnosis. They should really know that. We've had these themes over and over where sometimes patients are very confused about their diagnosis. Two let them start making their own appointments. And then start with that part, like just make your own appointments where your parents are not doing that for you. And third, take your own medications. They should have full autonomy of their medications. They should know what they are on, how often. And I know Doctor Steven has talked about that in her patients too. Ask them over and over like what this is the time we should be asking. And what they're doing and they should be able to answer without the parent or the caregiver being more in the periphery at that point. For the adult expert, when they are turning 18, accept the patient revisit appointment reminder access transition package prior to their first visit and then for the patient health status, awareness, independence. Transition and manage their appointment schedules.

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What are some helpful tools? I know you mentioned TRAQ. Would you want to tell us a little bit more about that? Yeah, sure. So TRAQ is a validated questionnaire that goes through different domains of self efficacy. It may look at a patient's ability to understand their own diagnosis. To be able to ask questions to a medical provider, to be able to communicate through different methods, whether making phone calls using the portal. There are questions too about, you know, levels of anxiety about all of arranging one's own health. So that's part of the Transition readiness assessment, but also in some ways the behavioral health assessment. There may be other formal measures that are used for these, two things. But I personally use the TRAQ questionnaire just to have something on paper. This is just a quick screenshot of the first of it so you can see that patients can answer anywhere from no, I don't know how to do this particular skill, or yes, I always do this when I need to. And the way that I use this is that if I see that they've marked yes to everything, then I'll say, OK, this is somebody who thinks that they are ready to fly. There is also a parent caregiver version of this. And so, especially if that aligns with what the patient is saying, that makes me feel a lot better. There are other questions where if the patient is saying, no, I'm not really sure. I don't know how to or the parents answers are different than the patients that I think that we have a little bit of work to do. I think once they get into the adult area, we like to also kind of meet them where they're at. And a lot of times patients will say, well, how are you going to know if I'm doing well or not.

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And this is where I say I need a bowel diary. And so I have encouraged patients to send me once I start a medication, a bowel diary. And a lot of times these apps, they're very easily accessible, they're fun. I know this sounds weird but they like actually documenting their bowels. And so, they can do that and they can upload it right to their portal and I can say, OK, they're on this and this is what's happening. Let's adjust based on what's going on. And then again, you can find a lot of resources online. There are some options here that we've put on the screen where they can maybe help be a part of their transition and picking out the providers that they feel comfortable with in addition to utilizing the resources that we are able to provide them.

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OK. So during the last stages of transition in terms of the responsibilities of the pediatric and adult providers, we think that at least in my practice, we set that six month window so that everybody knows that the time is coming and that there is a deadline because if there's no deadline then sometimes it keeps

on getting pushed back keeps on getting pushed back. So from my standpoint, I see my responsibility as ensuring that there's nothing that requires further history from the pediatric team who has known this patient for a very long time because I want to not reinvent the wheel. I also want to evaluate that patient for whether they need to meet other members of my team and because I work in a large academic center that might include dieticians, GI psychologists for my patients who require advanced nutrition support they may have to see a different provider like just for that nutrition piece. So otherwise, the things that we often start to think about at the first visit for the adolescent young adult patients who are coming to my clinic are how do we enable these patients to advocate for their own care. So the TRAQ questionnaire is one way by which I do that. I see where the patients think that they're succeeding and where they're unsure and they need a little bit more. One specific example that has emerged to me is the way that patients and their parents communicate through my chart or the messaging portal. Oftentimes at the beginning it may be the parent writing to me, and when the parent writes to me, I always make sure to include the parents name and the child or patients name, just so that they know we are sort of trying to include the child in that message as well. If it is the patient themselves who is writing to me all the time, then I consider that a pretty good marker that they feel confident that they can communicate with their new provider. And to me that's a good sign. That's just one example.

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Similarly, we like to make sure that the medical summary is set before our transition deadline, so we always discuss the transition readiness assessment at the first appointment. If there are needs that are identified, such as the need to formally involve a social worker, for example, that might be something that we try to think about during that six month window. My pediatric colleagues provide me with the pre-existing medical summary and I may not send them my full note back, but again, if I have questions or concerns then I can ask that of them otherwise. I'm not using a particular checklist for myself, although in the future we may see this evolve where we're using the TRAQ sequentially to see how patients change in self efficacy over time. And then lastly, counseling, so educating patients and caregivers for effective care. So we, as Kristina mentioned, recognize the key stakeholders in the process. We try to set expectations so that we know that if setbacks occur, it's not the end of the world. It just means that we're going to keep going, keep trying. We try to provide positive feedback to our patients during this time. Congratulating them on doing certain things for themselves, thanking them for sending messages, even though I don't like getting tons of my chart messages, but that shows that they are willing to communicate with me and then we always schedule the follow up appointment, the next appointment at the current one, just so that it doesn't become a situation where four months later they say, oh, now I really, really need to see you and we don't have anything available for three months. Good point.

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So the same case, I think we have done these themes, but how could we have done this process more effectively? Let's see, we could have reviewed the policy with DJ and his parents. We could have educated on the stigma associated with medication use, understand the future goals and ensure that DJ and his patients were comfortable with the transition policy. So then when he reaches 19, what are the next steps in his transition this would be again as we said, master medication medical history, learn to make own appointments, identify the providers and then finding different what the focus areas of needs are, establishing care with adults and moving forward. Like we discussed in the previous themes, develop goals and skill sets for DJ to develop throughout the transition process.

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Understand the medical system. Discuss his plans for college. Identify providers around him. And let's see here, so as a pediatric expert, send track assessments that we have done to the adult providers, send the medical summaries, ensure communication, confirm the date of appointment, first appointment with the adult provider. And as an adult provider, we would review those summaries that were so carefully crafted for us, conduct the initial visit, address the patient and caregiver questions and concerns, and then orient the patient to adult practice and review the differences in approaches between pediatric and

adult. Practices including practical aspects like scheduling, messaging, co-pays for appointments, etc. So I think this is important for all patients regardless of age is understanding that their care plan is a journey and that you're going to have ebb and flow, you're going to have ups and downs. Not everything is going to be at 100%. You may not get to 100% improvement. And so setting that expectation and then also when I was talking about the bowel diary, sometimes patients don't even realize they're getting better until they actually map it out and they see that they're doing better based on what the care plan and, being able to kind of be a part of that is important. Just a quick side note for patients with autism spectrum disorder, they may actually need some more time and follow up approaching their needs in the clinic, making sure that if they have sensory concerns, you're dimming the lights. I know that can be difficult to chart etc, but dimming the lights, quiet environment, putting them into an exam room as soon as they come in to the clinic and they check in, they're not sitting in the waiting room when there's a lot of things going on, having them listen to music while their caregiver gives them some options as well.

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After the transfer of care, what are the next steps to ensure a successful and complete transfer of his care to an adult provider? So as the adult expert, we assume now full care of DJ and we confirm that with the pediatric providers and as the pediatric expert, we confirm the attendance at the first adult appointment, obtain feedback from DJ, his parents and the multidisciplinary team on the transition process and then communicate with the adult care team and obtain feedback. OK.

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Are there other pearls for the transition of care that you would share with the audience? Kind of as a closing, I think one is engaging community specialists or social workers. As you saw, these are all arduous things that are going to take time and we do not have time on either sides in the busy practice and the patients we see. So maybe enlisting help of social workers in community engagement specialists. Two is different models of seeing patients. We need to come together and you know look at some of these. Kristina, you had mentioned the pediatric provider moving in on a Zoom call and checking in and or sometimes doing combined visits. Now combined visits will be hard on the same day because insurance will not approve or will not pay for both visits with the pediatric and the adult provider. So that might be hard, but you could think of a model where you do consecutive day visits or you a form. This is where I think AAP I'm happy to say that there's a task force that's coming together. I think all the societies realize that this is a big need. So there is a task force being developed between AAP, AGA, ACG and NASPGHAN where we are trying to understand that you know, we need to have a central body or a central governing guidelines for transition of care. So there might be, it's great that we might be having newer models getting established. In the near future and I think lastly, having this network or directory of specialists, that might be really important. We saw some of those other two. We usually don't use them in my practice. I'm not sure if the audience used that in their practice. Do you guys have registries or directories? Do you use GotTransition or ACG directory? So I think that's where just having a good knowledge base where we have this wealth of information stored for everybody might be useful. And I think don't forget your key stakeholders and remember that everybody is part of this team approach, including your nurses. Your nurses are going to be the people that really engage the patient in between visits. Start that conversation early, start that transition part early. So key takeaways including that include encouraging patients to take ownership of their health. We always are trying to empower our patients to do that, build those networks amongst providers and other care teams, including all the people that we mentioned and then developed standardized transition programs and resources, which is everybody's job and everybody's part of that process.