

## Emotional Aspects of PKD Including PTSD

Gillian: I'm Gillian Mayerson. I'm a pediatric psychologist specializing in dialysis, solid organ transplant and then I work in cardiology and our heart center as well at St. Louis Children's Hospital. I'm also Assistant Professor of Clinical pediatrics at the Washington University School of Medicine. So, just a disclaimer. The material here is being made available by the PKD foundation for educational purposes only. It is not intended to represent the only necessary or the best methods, procedures, just their disclaimer for any liability and things like that. I have no relevant financial disclosures. So, like I mentioned, I'm a pediatric psychologist, I received my Doctor of Psychology in clinical psychology from Nova South-eastern University in Fort Lauderdale, Florida.

My primary area of specialization is in pediatric chronic illness, specifically end stage organ disease, dialysis, congenital heart conditions and solid organ transplantation, my clinical interests our patient and family adjustment to in coping with chronic illness, adherence to medical regimens, emotional concerns, such as anxiety, depression, medical trauma, related to chronic illness, and then pre transplant psychological evaluations. My research includes post traumatic growth, quality of life and then quality improvement related to psychology programming. So, our agenda for today, we're going to talk a little bit broadly about adjustment to chronic illness, and then unique issues in pediatric chronic kidney disease, a little bit about emotional and behavioral health, red flags, and then some interventions and what parents and caregivers can do.

So, this was from a recent article by Aier, Pais and Raman in 2022, actually, and it talked about how childhood chronic kidney disease is a complex condition that requires a lifetime of medical treatment. So, it comes with disease risks, and invasive medical procedures. And we know that children with CKD are at risk for emotional, behavioral, social, and academic difficulties that significantly impact their quality of life. We also know that caring for children with CKD can be stressful for families. So, this visual, I think, really nicely kind of describes that and sort of shows the bi-directional relationship between psychosocial challenges, the impact on the family, and

## Emotional Aspects of PKD Including PTSD

then the impact of the family on psychosocial challenges. So, these unique challenges are crucial and can negatively impact treatment outcomes.

You probably could draw a bidirectional arrow here, back to health factors and psychosocial things. So, awareness of and addressing these evolving psychosocial issues is important and can help with developing needs. So, we know that management involves not only assessment in terms of routine psychological evaluation and assessment, but also therapeutic intervention for children, to support they're not only their physical, but also their mental wellbeing. So, when I'm thinking about a patient that I'm working with in a family, I'm using Bronfenbrenner ecological model, and it's really been central in guiding the understanding of risk and resilience as development unfolds. And it's important to contextualize view of child development and child treatment. So, it provides us insight into working with children and adolescents and even adults who have a chronic medical illness.

And the influence that multiple systems such as the extended family, neighborhood healthcare systems, school and community have on the child's interaction on their psychosocial functioning. So, this model really helps me as a psychologist examine all of the subsystems of the child's world that play prominent roles in their adjustment and outcomes. So, this eco system Exosystem excuse me model really is something I think about for our patients who end up admitted to the hospital right or coming here frequently. We are a part of their support system as well and their relationships with medical teams is a big piece of that. So, in terms of adjustment to chronic illness, we know that there are adaptive tasks for children and families when it comes to adjustment. So, first and foremost is dealing right with not only stress associated with treatments, side effects, hospitalizations, but also with symptoms of the condition pain, discomfort, functioning.

Then there's establishing. Establishing a working relationship with a medical team, depending on what age you know, diagnosis occurs at preserving. So, striking that good emotional balance between managing upset feelings maintaining hope. Sorry, I'm seeing a couple questions in the chat. So yes, I am a pediatric psychologist. So, I'm coming at this from a predominantly

## Emotional Aspects of PKD Including PTSD

pediatric approach. I will talk a little bit about, broadly about caregivers. But yes, this is focused on children. So, really thinking about self-image, sense of confidence and mastery, readjusting either as a patient or as a caregiver, goals and expectations in the face of changes of functioning as that occurs, and relationships with family and friends, and then preparing for uncertainty. Oftentimes, I hear from patients and families, that uncertainty is one of the most challenging parts of not knowing what they don't know, and not having a crystal ball that can make adjustment challenging.

So, there are many factors that impact emotional functioning, motivation. We see this more in adolescents' temperament, do you have a child who was always a little bit more anxious or a little bit more irritable, problem-solving skills, social support, family resources, parents and caregiver adjustment, peer relationships, self-esteem and self-advocacy, family cohesion and relationships, major life events, we don't live in bubbles. And so we can't parse out, things happening with our chronic kidney disease at the same time as things, moods, deaths, global pandemics, illness severity, previous healthcare experiences, I find this to be a big one, have there been, and we're going to talk a little bit later about medical, traumatic stress and PTSD, have there been multiple negative experiences within the healthcare system, and then previous emotional functioning or behavioral functioning difficulties.

So, some signs of positive adjustment, being open to recognizing challenges, and that people are functioning as well as possible, I always talk about with my patients, the idea of functioning in spite of symptoms, I can't control what is going on, medically for a patient. And oftentimes, they can't control that, but what they can control is doing the best they can. So, if that means only going to a half day of school three days a week versus five full days, that's still functioning the best that they can, trying to anticipate and prepare for the future. And this is where that relationship with the medical team is so important. So being able to have an open and honest conversation about what the journey might look like. As you know, CKD progresses willingness to access resources and ask for help. And this is bi-directional as well.

## Emotional Aspects of PKD Including PTSD

So, if you're a medical provider, who happens to be you're listening to this talk, right, having handouts about psychosocial issues, and psychosocial resources, social workers, child life specialists, psychologists, knowing what you have access to as a patient within your hospital system, and then saying, we're not okay. Or I think we're moving towards not being okay. And then also age appropriate and normative behavior. Anxiety is a normal emotion. Anger is a normal emotion, happiness, sadness, right? They're all normal emotions. And so, it is normal for all of us as humans to have varying reactions over time. It's when those symptoms stick around for a while, that may start to become an area of concern. So, there are some unique issues that the literature talks about in terms of pediatric CKD and emotional functioning.

So, I'm not news to you all but you know, adherence to medication, diet and fluid. Most kids, teens, young adults aren't having to think about taking meds or fluid goals or fluid restrictions depending on and their medical course, some of the physiological symptoms of CKD can mimic mask and our cause psychological issues. So, thinking about medication side effects on high heart rate, high blood pressure, a lot of that can feel like anxiety and knowing how to parse the two out medical visits and interventions, having to miss lots of school. And then also, one of the most unique aspects is that the parent or the caregiver may also have PKD. And so that's a really unique component to this. So, when we think about health-related quality of life, we know from the literature that youth with chronic kidney disease can have significantly lower quality of life, in several domains physical functioning, social functioning, emotional and academic functioning when compared to healthy youth.

And we also know that older age may be associated with lower school functioning. So, thinking about teenage patients, having to miss more school, or potentially wanting to avoid situations with peers, not feeling like they can keep up physically at school leading to miss days of school, things like that. We also know from the literature that longer disease duration, so the longer that you've been diagnosed with a condition and being older, was associated

## Emotional Aspects of PKD Including PTSD

with higher quality of life and physical, emotional and social functioning. And some of the hypotheses behind this are that, as you get older, you're able to process more understand more abstract reasoning, you have found things that work well for you in terms of coping with your disease, physical symptoms. And in a recent 2021 study, the school dimension was the most effective quality of life domain.

For patients, I do wonder, and the study didn't touch on this, what role Covid plays in that as well, depending on if a patient has had a transplant, or is for other reasons, immunocompromised, they might have been doing homebound, or home-schooling for longer periods of times, which definitely could have a negative impact on quality of life. So again, not news to you all, but the impact of PKD that's physical, the things that in this study, teens and kids pointed out as being the most stressful for them, hypertension, pain, urinary symptoms, for a lot of my patients who have to self-catheterized, being able to feel comfortable in doing that at school or talking about two and about peers, physical activity and functioning limitations, potentially diet for my patients on dialysis, that renal diet and fluid restrictions, definitely one of the highest areas of stress and frustration, especially in the summertime, when it's hot, and just wanting to be able to drink the fluids that you want to drink without really thinking about all of that.

So, in terms of school and social, this study by Oberdhan, really had some interesting quotes from patients. So, in their study 18% of the sample miss school because of their kidney disease. And they felt uncomfortable at school, two of the quotes from the article that really stood out where it takes a lot out on a kid and like, I don't know basic things, because none of the teachers wanted to teach me after I got back, and it has a really big effect on children because their learning is really affected by it. And that's probably my biggest concern. So, part of a patient and a parent's response in that. So, missing class, we also know the impact, that there can be challenges in learning related to chronic kidney disease to sort of that double whammy. And then social so not wanting to engage in some activities with friends,

## Emotional Aspects of PKD Including PTSD

keeping the condition secret to try to avoid teasing or to avoid feeling different.

In terms of emotional functioning, these two articles talked about how many patients adapt to the fact that they have a progressive chronic disease, and really this desire to want to be normal and not wanting to think about it. Three to 18% of patients in the study reported feeling nervous, frustrated, sad or worried about their disease and about their future. They did endorse some problems with accepting diagnosis initially being worried about their kidney health, and that depression can be more common in patients with PKD. We also know that there's an impact act on caregivers, right? There is an emotional impact. So, guilt, anxiety and worry depression. Particularly that guilt piece can be relevant if a parent also has PKD. And they feel that it's determined there's a genetic component to it.

Social and Family impact so marital relationships, we do know that the strain of living with chronic illness and having a child with chronic illness can lead to significant strain in marital relationships, friendships, feeling like you're doing so much for caretaking, and all of these other activities of hospital visits, and hospital stays or dialysis that friendships can be one of the first thing to fall to the wayside. And then siblings not really within the context of this talk, but I could probably do a whole presentation alone about siblings and sibling coping. Siblings, sometimes taking on maybe a more mature caregiver role. At a young age, feeling that burden or potentially feeling I've heard invisible or left out. And then of course, the financial impact that multiple things in medical care prescriptions, again, probably something that could be a whole presentation as well.

So, this study by Simmons talks about parents who had PKD and 62% of the adult patients who had ADPKD felt guilty about passing their disease on to their child. And there was a clinically significant depression and 22% of the sample. And that worst kidney function, they used EGFR led to lower quality of life. So, probably not surprising to anybody. And then the participants in this study talked about their concerns about talking openly regarding their diagnosis, in particular, if their child also had the diagnosis in terms of what

## Emotional Aspects of PKD Including PTSD

that might look like with the child's progression, hiding it from friends, or avoiding conversations with significant others. So, in terms of emotional and behavioral health, red flags, and kids, there are a couple things that I think are important to look for when thinking about those emotional functioning aspects.

So, treatment fatigue, this looks like lots of barriers to medication adherence or to diet adherence statements, like I hate taking meds, I'm sick of taking meds, I just want to be like everybody else, I feel angry whenever I have to take meds. And these might be some of the warning signs leading into significant non-adherence, right sort of the, hopefully the cue to catch that some additional support is needed. In terms of some of those areas. When it comes to depression, there are many depressive symptoms like changes in sleep, changes in appetite, low energy, that overlap with some of the symptoms of having chronic kidney disease, and it can get difficult to parse out, chicken or egg and which comes first.

So, then I'm looking for some of the ones that maybe don't overlap with the physical and irritability, oftentimes in young children. And even in teens. Depression looks more like irritability than it does sadness, negativity, withdrawing and isolation. So, not wanting to be with friends or family pulling up in a room, kind of more than usual, and less enjoyment or less pleasure and things they used to enjoy. And this is known as Anhedonia talks of death or harming themselves. And this one is interesting for a patient who has a chronic medical condition. It is not uncommon for some of my adolescent and young adult patients to talk about death, but there's a difference in talking about death and talking about wanting to die.

And talking about wanting to die or wanting to harm oneself or engaging in any self-harm behaviors is definitely a big red flag. And then changes in academic performance, lower grades, sleeping in class, skipping school, anxiety, some kids really don't recognize anxiety and have a hard time verbalizing that they're worried. So, this is in younger kids typically will see tantrums over little things, rigid routines, rituals having to do things a certain way. For all of us as humans, but in for in particular for kids' control is really

## Emotional Aspects of PKD Including PTSD

important for them. And so, feeling like things are out of control in terms of their health and what's happening to their body. They can look to have control in other ways. And so that can lead to some rigidity. That's potentially driven by anxiety, excessive worry, lots of what ifs and asking lots of repetitive questions seeking reassurance.

Problems separating from caregivers, right? So, you've got that kid that you can't even go to the bathroom without them following along with you. Sometimes this can occur after a hospitalization or after a particularly stressful medical procedure. Looking kind of restless so always moving edgy. We'll talk about hyper vigilance is a piece of medical traumatic stress here in a minute trouble concentrating, being tearful, overwhelmed.

Speaker 2: Julian, I want to let you know you have about 10 minutes for preceding presentation, thanks.

Gillian: Thank you. So, medical traumatic stress, so kids' response to medical trauma is often highly related to their subjective experience of the medical event rather than the objective severity. So, this is one of the you know, kind of most unique parts, seemingly a flu shot to one person could seem like not a big deal. But to a child having a flu shot, having a vaccine, etc., etc., sort of all of those repeated experiences can lead to trauma. So, medical traumatic stress is really the set of psychological and physiological responses to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. Many ill or injured kids in their families up to 80% can experience some traumatic stress reactions, following a life-threatening illness or painful medical procedure.

And between 20 to 30% of parents and 15 to 25% of children and siblings have some persistent traumatic stress reactions that impair their functioning and affect treatment adherence and recovering. It is important to differentiate between stress and traumatic stress, stress is having a bad day or having to do a hard thing, whereas traumatic stress is being fearful of your safety or wellbeing. So, we know that anxiety about medical care can be a piece of traumatic stress, in particular needle anxiety. So, lots of seemingly quote

## Emotional Aspects of PKD Including PTSD

unquote, small hurts can become intolerable over time. And these things can really impact that day-to-day functioning, sleep, social relationships, academic functioning, impact adherence. Many of us may have heard of the kid who refuses to get out of the car at the doctor's office or, unfortunately ends up being held down for procedures, which creates more trauma, and then impedes optimal recovery as well.

So, four main types of traumatic stress reactions to re-experiencing keep thinking about the trauma, a lot, even when you don't want to some re-experiencing is normal and natural. But too much re-experiencing this is where we're thinking about nightmares or flashbacks can also lead to physical symptoms. So, sometimes kids will say, it just keeps popping into my mind, where it feels like it's happening again, or I get upset when something reminds me of it, which is really hard, when you have to keep coming back to the place where the traumatic things happen. Avoidance, this starts by trying not to think or talk about the trauma, or anything connected with it. So, sometimes we want to stay away from things that remind us and that leads to new fears or worries. And this become can lead to becoming more aware of safety.

But avoidance can really interfere with daily life and stop a kid or caregiver from getting back to enjoying things that they use. They usually like to do an increased arousal so hyper arousal is usually that natural fight or flight response that we all have, but then the fight or flight doesn't turn off. So being jumpy, hyper vigilant, having a heart racing, can't concentrate, can't sleep, and then dissociation so detaching from situation, feeling like you know the situation feels unreal or they can't remember parts of it. Other traumatic stress symptoms, reliving events, nightmares, lack of positive emotions, hopelessness, withdraw, irritability. So, in terms of interventions, and what parents and caregivers and medical providers can do.

So, in terms of strategies for trying to prevent traumatic stress for providers, it's trying to find ways to reduce pain and distress. Talking about ongoing feelings and reactions, refocusing on unhelpful beliefs, and really having that strong relationship. And for a patient and family, it's thinking about

## Emotional Aspects of PKD Including PTSD

increasing coping skills, ways to reduce anxiety, increasing social support, and then increasing family communication. We know that those who struggle most tend to focus on the past and what they've missed things that they can't do the most distressing aspects of the situation. Avoidance, avoidance in the short term is a great coping strategy, but in the long term ends up causing more distress. Oftentimes, patients and caregivers who adopt the belief that they're helpless and tend to have more challenges with emotional functioning. So, I'm owning the story of you. Right? And focusing on more positive or helpful doesn't have to be super positive.

I call this the yes and right. Yes, this is really hard. And I have these great supports to help me. Yes, I had really traumatic experiences in the hospital. And I know that, I'm going to get the help I need to versus a yes, but where we don't validate all those emotions and experiences we're having. So, interventions for the patient, psycho education, right, so giving education modelling, talking about different situations, teaching self-care skills, things that they can control, they can work on. relaxation skills, mindfulness, deep breathing. I'm in therapy, right I'm in psychological intervention working on cognitive coping strategies such as positive self-talk or reframing unhelpful beliefs. Acceptance and Commitment Therapy as a type of specific intervention that really functions you know focuses on living a valued life and acknowledging emotions and experiences but not letting those things run the show.

And then school readjustments attending school for shorten days, tutoring, having a buddy having a section 504 plan or an IEP, so that the patient is able to go to school, and get those social interactions and still learn but meet them where they're at physically. So, interventions for the family, for parents, sometimes connecting with other families, that can be done through your medical team or the hospital, or organizations like the PKD foundation. Sometimes family therapy is necessary, looking at parent management training, looking for practical resources through social work or financial supports within a hospital. And then sibling support giving siblings

## Emotional Aspects of PKD Including PTSD

education, potentially support groups for siblings, and then even brief involvement in counselling.

So, some of the things we know that parents and caregivers can do help supervise and support especially when it comes to adherence have contingencies it is okay to still have rules about positive health behaviors and consequences for poor choices. That's really promoting that yes, I know you have a medical condition, and we still have appropriate expectations. Trying to problem solve this is hard and we can problem solve through it. Modelling optimism and don't say it could be worse focusing on what can be controlled or changed and what can't there's that and instead of, but I talked about and reinforcing and modelling coping behavior as a family have a time for mindful minute sit down together, teach relaxation, all of those kinds of things.

So, some resources the National Child Traumatic Stress Network is where I got a lot of that material on medical trauma. Psychology Today is a great website where you can search by insurance, your location and for finding a psychology provider, and then talking with your medical team or if your team has a psychologist or social worker to sort of parse out, is this normal adjustment or is it something we might need some additional help and support with? Thank you, guys, so much. I'm happy to take comments, questions. My contact information.

Speaker 2: Not seeing any questions on the chat yet. If there's any you guys are welcome to type them in now. Gillian has little bit of time to answer them. Gillian I'm not seeing any. But thank you so much for your presentation, that was very informative. They did click the link to the survey and the chat, and everybody would make sure to take that, that would be helpful too. And if you are looking for your next session, session starts at 5pm. And those are living your best life for Transplant disease management for children, Transplantation overview and understanding polycystic Liver Disease. Thank you all for joining us today.

*[Audio Ends] [00:58:00]*