

Mental Health

Dr. Daniel: Hi there everyone. My name is Daniel Cukor.

Stephanie: I'm Stephanie Donahue.

Dr. Daniel: We are here today to talk about some of the mental health challenges and the title of our talk is Mental Health - Facing the common challenges. So, before we begin, let's just show this activity disclaimer. All the content that we are about to present is purely our own. And similarly, in terms of the disclosure, neither Stephanie nor I have any relevant financial relationships to disclose.

Stephanie: I'd like to introduce Dr. Daniel Cukor. He is the director of the behavioral health program at Rogosin and has devoted his career to studying mental health in patients with chronic kidney disease.

Dr. Daniel: Let me introduce my colleague here. This is Stephanie Donahue. She is a nurse practitioner, and she has a long and devoted career working with people with PKD, both as a care provider, as a researcher, and as an advocate for them.

Stephanie: Thank you, Dr. Cukor. So, I'd like to first explain to folks how we focused our talk today. And we certainly talked about a number of issues that I have long felt are relevant to people with polycystic kidney disease. And we found ourselves choosing to focus on an article by two dietitians interestingly enough, Tiffany Ma and Kelly Lambert. And in their project, they sought to answer the question, what are the information needs and concerns of people with polycystic kidney disease? And so, what they did was they constructed a survey, and they looked at online questions and Facebook and other forum posts by patients with polycystic kidney disease.

Once they develop the survey, they then distributed it to PKD social media groups on Facebook. They received 536 completed surveys. And they discovered that there were some needs expressed by the folks who completed the survey. So, the major information needs that were expressed were for dietary information, information regarding medications, and medical management and symptom control. And included in the survey were free text responses. And the themes uncovered from the free text responses were to the question of the major challenge of living with PKD, was learning to

navigate dietary ambiguities, managing social, psychological, and emotional needs, and accepting an uncertain future. And so again, we chose today to focus our talk around these identified needs for the PKD population.

Dr. Daniel: So, the first topic we're going to talk about today is learning to navigate dietary ambiguities. And we've kind of divided that up between kind of knowing what should I do and then follow up is how do I go about doing that? So, for the first part, we'll turn back to you, Stephanie.

Stephanie: Thank you. So dietary ambiguity and dietary recommendations. So, as you mentioned, I have a fairly long career in caring for folks with polycystic kidney disease about 20 years. And I have to say, I don't remember a time where there weren't dietary ambiguities, low sodium, low protein, whole foods, caffeine, no caffeine it could make your head spin and I think certainly all well-meaning. But some of the recommendations are more rooted in science than others. And while I will talk a little bit about that later, I think it's important to recognize that when you have so many different sources of information online, in person, in print, what you're reading, the blogs, folks that you know, support groups, your own team. It can cause anxiety when you find so many different sources with so many different recommendations, and they don't all line up together.

So, as I said, different information from different sources with no obvious answer can lead to uncertainty. We may not know what to expect, what can happen, and what to do. We may feel we have no control and no impact on the outcome. And whatever happens, we might feel is happening to us instead of maybe because of us. Again, less control. And this may make our illness or polycystic kidney disease feel out of control, and make us feel vulnerable, and increase our anxiety. So, while ambiguity certainly does exist, there's no question. And different providers may recommend different suggestions on diet. I'd like to talk a little bit about things that you can do to hopefully decrease your anxiety a little bit around this.

Get more information. So, work with your team, your nephrologist, your nurse practitioner, your nurse or dietitian, certainly your dietitian to help figure out what might be the right diet for you. The right diet for your friend

with polycystic kidney disease may not be right for you. The recommendations from the person on the blog who may or may not have polycystic kidney disease may not be right for you. So, talk with your team who knows you, who knows the disease, and who can give you some recommendations that are rooted in either good science, either in anecdotal things that they've seen, but certainly in more than sources that may be unknown.

Start following the basics. So often, in my time, I've seen people who come to me very anxious about diet. What can I do? How can I keep this disease from growing? I've heard that I shouldn't have caffeine. Many of these people are not aware of the basics and or aren't following the basics. So, I would say start with the basics, a solid, kidney-healthy diet that we know can be beneficial across diseases that cause chronic kidney disease. And by knowing these basics, this foundation of a healthy kidney diet, you can decrease your anxiety a little bit hopefully knowing that you're doing something to keep yourself well. And I've included here a trusted source of kidney information that gives some dietary recommendations.

Explore clinical trials. So organized clinical trials are generally vetted by an institutional review board. They are reviewed annually, and they are organized in such a way that the potential benefits and the potential risks are made clear to the participants. And so, you and your team can review that and decide if it might be right for you. I would suggest that if you're considering a clinical trial that you explore the National Institutes of Health website, clinicaltrials.gov, which is a Clinical Trial Registry, that is widely accepted in the scientific community as a source for clinical trials.

Then finally, I would say look at your circumstances we know that so much of anxiety comes from the unknown and not being able to predict what's going to happen, what we're dealing with, I would say, look at your circumstances, and list the things you can and cannot control on paper, in your computer, in your telephone, whatever works for you in your head. But look at what you can control and what you can't control, then make a plan with steps that include things you can do in the areas within your control. So,

for example, you know that one of the things of a kidney healthy diet, particularly with polycystic kidney disease is fluid intake staying hydrated, make sure you drink your water every day, you'll go to bed at night knowing I've kept myself hydrated. I know there's science behind that and I have achieved that today. And so, I think when we acknowledge the things we can control, and we do something about them, that can certainly at least decrease the anxiety that we're feeling around the situation.

Dr. Daniel: Thanks, Stephanie. So, my part of the talk for this part is to really think about how do we stick with a diet plan or what can social science offer in terms of suggestions or tips as to how to stick with a program in the long term. So, the two questions that I will address here is how do we help ourselves want to stick to a plan is number one. And then number two is okay, if I have chosen a plan, and I'm trying to stick with it, how do I increase my odds of doing that. So, for both of these, I'll provide a little social science background. So how to want to stick to a plan?

So, where my mind goes is back in the 1980s, Prochaska and DiClemente wrote this paper, which was rather influential, and they call it the transtheoretical model of change. And they really looked at how is it that people go about changing their health behaviors, and they started off talking about smoking cessation. And then since then, in the last 40 years or so it's really been extended to all different types of health behaviors. And what they've identified is that there's really a pattern that people go through in the decision of how to change. And here's a model of what their work highlights.

So, starting at the top over here, people begin often in the pre-contemplation stage, which is even before you started to think about it, about behavior change, no intention of changing your behavior so, I'm kind of happy living my life. And then something might happen, where we get pushed to a contemplation stage, become aware that a problem exists. And then we just kind of realized, oh, maybe there's something that I need to do. Maybe it was when you got your diagnosis, maybe it's listening today to the talk, there's something that happens that kind of rocks us out of our denial or our complacency and says maybe I really should do something about this.

Then we move to the next phase, which is called preparation, which is alright, let me do my research. What should I do I want to have a PKD healthy diet, what does that look like? What should I do? Who should I speak with? So, Stephanie has given us a lot of great tips already about, you know, once you're getting prepared, how to go about doing that. And then there's the action phase. And this is usually what people think of is when they say, okay, I'm going on go on a diet, they kind of just jumped to the action phase, like, okay, I'm going to go do it. So, this is the doing it part. But as you can see, it's just one part of the larger model here. Because doing it without having the thoughts beforehand, and that time to put into prepare, really doesn't set you up for success. So, once you've decided on what you would like to do, then you begin to put it into action, okay, I'm going to drink this many cups of water a day, I'm going to reduce my sodium intake by this much, whatever your plan might be, then developing a strategy for implementing that plan.

Then the next phase is what we call maintenance. So, in the beginning of every good plan, we are very motivated, but we need to have a plan for how do we kind of hold on to these behavior changes, it requires an intensive amount of effort, consistently, we're probably not going to stick with it just knowing ourselves as human beings. So, we need to find ways of kind of incorporating it into our lives. So, for dietary change, that might mean, we shop differently, it might mean we eat out in different restaurants like that just becomes part of our repertoire, so that we're not constantly forced to deal with some of the challenges or temptations of eating off of our dietary plan.

Then I think most importantly, perhaps, is the idea that there's relapse, right like that. There's never, it's not like, once we figure this out, human beings go on and then say, okay, that's never been an issue for me ever since then I've committed to doing it, and then I just did it and that was the end of the story. We all know that no matter what it is that we try to change, there are always moments where we slip back and if you look at the picture here, it's really meant to show it's a circle. It says in the middle there, it's an upward spiral. And we're supposed to learn from each relapse.

Mental Health

So, we tried to eat healthy, and then we might have some time where we're like, not eating that healthy, and then again, we kind of lapse into that pre-contemplation stage. And then hopefully, something will kick us out of that and say, you know, either my lab values have changed or put on a little weight, or I'm just not feeling as healthy as I was before. Let me kind of reexamine again. And then again, we go through this process again, and each time around, it becomes actually easier and easier instead of harder and harder. Because we've been down this road, we know what we should be doing. And it's just about finding new strategies to kind of get us on that path again.

So, the second thing that I want to talk about is how do you stick with a plan, essentially that has a distal reward which means that the reward is down the road, but it has short-term negative consequences. Or another way of saying that is I know what's better for my long-term health, but it looks so good. So, this is a challenge that anyone in behavior change, especially if we're trying to do things that are healthy for us in the long term. But you know, we're giving up something in the short term, you know, how do we go about sticking with that?

So, for that, I'd like to turn toward B.F. Skinner: Operant Conditioning. This is a strategy that he used with animals, but I think it works really well for ourselves, as humans, and it's something that we can do to ourselves, to help us stay motivated. So, the basic idea is that people learn to associate a behavior with its consequences. So, if there's a short-term positive consequence, we tend to do that more, if there's a short-term negative consequence, we tend to do it less. So, giving up our food that we like to eat, we're not eating in the restaurants that we like, those are unpleasant consequences. And if we, you know, if that's all that we have, and just we're stacking the odds against ourselves up, this is a behavior that's going to last, we tend to do things that we like doing, those are the things that get reinforced, those are the things that we stick with in our behavioral repertoire, the things that we do.

Mental Health

So positive reinforcement. There's a lot of science here, but the important parts are that the positive reinforcement is something that is added which increases the likelihood of a behavior. And we know, from reward theory that if we're trying to reward ourselves, the reward should be immediate. It should be every time the behavior is displayed, and it should be something of meaning. And if we are able to find something like that, then we're really able to learn very quickly. So, this is kind of an opposite situation where we have a long-term positive goal. So, to use what this learning model would be to really find a way to incentivize ourselves in the short term to stick with a long-term plan that we like, and here's my suggestion is that for most people, for most adults, if you ask them what is it that would incentivize you? What is it that motivates your behavior? They usually have kind of the same answer, which is cash, it's money.

So, the question then becomes, how much money would it take for you to eat healthy at this meal? So, for example, let's say we're at a point where we're struggling, we're not sure what our dietary choices are, and someone might come and say, I'd pay you \$100 right now to make to choose dinner A as opposed to dinner B. I think for most of us, that would be a pretty strong incentive to do that. And if they paid us \$100 for each meal, we'd probably stick to the diet a lot better than saying, what, in a few weeks, I'll feel a little healthier or I'll end up living longer in 25 years or 40 years. So, bringing that reward really close helps. So, the way that I think we can kind of capitalize on the strategy is to find what you think the dollar value is for you, whether it's every meal or at times that you struggle, and actually put aside a certain amount of money for yourself each time you're able to achieve that.

So, you know, as an example, if it's \$5, for each meal that you choose to eat healthy, put that into an account for yourself, where you kind of earmark it for spending it on something that is a luxury for yourself. And to stick with the program you want it to be every time that behavior is displayed, it has to be immediate. So, it could be a vacation fund, but that often takes it's a lot of \$5 meals to get to a vacation fund. Maybe there's something even shorter, something each week that you reward yourself with that is something of an indulgence and then commit to like actually doing it. And what you'll find is

that, yeah, it feels good to eat healthy because we know we're doing the right thing. But it also feels good after two or three months, when you're starting to have all of these little rewards start to pile up that begins to fill our lives with some nice positive encouragement.

So, moving on to the second kind of concept that the original study had identified of areas that PKD patients would like to have more information on, its managing social, psychological, and emotional needs. And today, we're going to be talking about focusing in on depression and anxiety. And I'll be speaking first about depression. So, Aaron Beck is a psychiatrist who actually passed away recently, and he is widely considered the father of cognitive behavioral therapy. And what he observed is that when we have a belief system that bad things are internal meaning due to us, they're global meaning they're pretty widespread and stable, they're unlikely to change.

People that have beliefs, that bad things are internal, global, and stable tend to end up becoming depressed. He has this triangle that he created, which is that negative views about the world, negative views about the future, and negative views about oneself, kind of come together to form what he calls depressive genic or depressive thinking, it puts us in a place where we're going down a path or more, we just going to start to feel bad about ourselves.

So, just as an example of how that might work. The first example is a made-up scenario here. I failed that exam because I'm not smart enough. I'll probably fail the rest of the semester. I'm not cut out for this. So, a student who has that mindset thinks about how they might kind of respond and move forward after that bad grade. As opposed to a student who says, I failed that exam because it was unusually hard. I'm going to have to do well on the next exam to save my semester grade. I can do this, but I will need to change my studying. Again, just a difference in perspective. But really in the first example, that student is going to come out unmotivated and if I had a guess unlikely to do better on the second exam, as opposed to the student in the second example, is more likely to do well on the second exam.

Now, perhaps a more relevant PKD example, is, of course, I'm depressed, this disease is internal, it's literally inside of me, it's global, impacts every

area of my life which seems to be the point of the presentation, and stable. And maybe stable would be okay, it's actually progressive it's even worse than stable. So, if you have that mindset, it kind of makes a lot of sense that people would feel depressed, as opposed to a mindset where you say, I have a genetic condition with how I respond to it is up to me, the condition is due to bad luck in the genetic lottery. I still have many areas of my life I can achieve everything I would like doing. The course is really unknown, but I should certainly not be wasting any of my most precious resource, which is time. I work with people that have PKD and I see examples, literally every day of people that are more like example one than people that are more like example two, and you know, the power of our mindset and our attitude cannot be underestimated.

Another note is that even if you start off coping pretty well it's a long-term progressive illness. There are just going to be moments where we're going to feel down. These thoughts have a way of creeping up and encroaching on us. So, if you're feeling you're a bit overwhelmed, or you're feeling things are too much for you, that's I think, pretty par for the course. And Stephanie will speak a little bit about the types of help that are available, but I think as at least a step one is to acknowledge that this is a lot that you're going through and that there will be times where it feels a bit overwhelming.

So just some strategies to help combat depression. There are behavioral techniques which are kind of similar to what I talked about. The diet is building in rewards into your life finding things that you enjoy doing, and just sprinkling that into your life. We sometimes call those mastery experiences because it's not really only about just the enjoyment, it's really about the satisfaction that we feel about doing some of these activities. So sometimes our lives get a little smaller, when we're not feeling well, we just kind of save our energy for the things that we have to do. But it's often those things that we like to do that really make life really enjoyable. So, kind of taking stock of that and then prioritizing and pacing. If you're feeling like you're kind of limited in the amount of energy that you have, or the certain things that you can do, really making sure that the things that we do put our effort into are really the ones that are worthwhile to us.

I spoke a bit about challenging some of those unhelpful thoughts. And you know, that's something that either you can do yourself, you can do with a therapist, but it is a very powerful technique. I encourage you to really pay a lot of attention to the tone of your internal narrative. Is there a negative voice always inside of you, which basically is telling you, you're fighting the inevitable, that is a really negative influence in a person's life as opposed to a positive voice inside your head which is encouraging you to do all that you can. And Stephanie.

Stephanie: Thank you. So, just to take a few minutes and talk a little bit about anxiety. So, anxiety is something that I have seen certainly, as Dr. Cukor mentioned every day talking about depression, I certainly see anxiety in my patients every day, across all stages of chronic kidney disease. And across all points in someone's illness. Anxiety, general anxiety can be defined as I have here, frequent anxious thoughts and worries that are out of proportion for the situation, and negatively affect our ability to function. Health anxiety is very similar, but it's about our bodies, our illness, our symptoms, a change in our symptoms. So often, I'll see a patient and they'll say, you know, I have this twinge and I'm not sure is it just because my kidneys are so big? Do I have an infection brewing? Do I have a stone that's moving? Do I have a cyst that's bleeding? What do you think it is? And it brings up all these possibilities for the patient and all this anxiety. So, I think, certainly, health anxiety is something that I see every day, frequent worry about the illness or body or symptoms, or changes that often affects people with chronic illness.

People with chronic illness like polycystic kidney disease are at an increased risk for anxiety. Some estimates are by 40%, or more, more likely to experience anxiety than people without chronic illness. That's substantial. And why is it important? So many people say to me, no, I'm fine. Yes, I'm anxious, but I'm fine. You know, it's okay. I'm still going to work. I'm still taking care of my kids. I'm still doing things that I want to do. So, before I worked with people who had polycystic kidney disease, I took care of folks with anxiety. And so, so often, this is what people would say to us and I had a colleague who called anxiety, the limp along disease because she said, these are the people who are in bed so depressed that they can't get up. Right.

Mental Health

These are the people who come to work who come to the PTA meeting who go to the birthday party, but they've got chronic headaches. They've got blurred vision, a dry mouth, they've got their heart pounding out of their chest, their heart racing, GI complaints, symptoms, numbness, and tingling, but they're there and they're doing what they need to do. Sometimes they're not there, but oftentimes they are. So why are we so concerned with anxiety? I'm so concerned with anxiety for a number of reasons, not the least of which is I think that anxiety can prevent you from doing the things that you want to do and achieving the things that you want to achieve. But in chronic kidney disease, a number of studies have shown that anxiety correlates with the quality of life, quality of your life correlates with your having anxiety or not. It also correlates with adherence to medications to your treatments, it correlates with hospitalization.

So, people with chronic kidney disease who are anxious have been found to be hospitalized more often than people with chronic kidney disease who are not anxious and with mortality. So, it is critical, in my opinion, that we look at anxiety and identify it early and treat it. So, I have never read a book, read a scientific journal article. Talk to a psychiatrist, psychologist, anyone who has told me that if you ignore anxiety, you don't deal with it. You put it off, it will make you better, it will improve things. No one has ever said that. And I think there's good reason for that because I don't think it is helpful. And it can be scary. But identify it and treat it early. Enlist the help of somebody, family, friends, or professional. Yes, I'm having some anxiety, some anxious thoughts. Let's do something about this.

So, there are a number of things you can do self-help very basic. Get your sleep whatever it is your six to eight hours sleep. Hydrate, eat a healthy diet, and minimize stimulants like coffee, tea, and sodas. Minimize recreational drug use of marijuana. So often people are using different CBD products now. Those are often short-term fixes. Non-pharmacologic treatments, yoga, meditation, mindfulness, imagery, have all been shown to decrease anxiety and if you practice them regularly, can be significant.

Pharmacologic treatments often time the first thing we look at for depression and anxiety are what's called SSRIs. So, the selective serotonin reuptake inhibitors and in people with chronic kidney disease, they often are a go to medication. I would say obviously, you need to talk with your doctor, your nurse practitioner, your treatment team about pharmacologic treatments, but if you feel like the self-help the non-pharmacologic are not helping you, then oftentimes the pharmacologic will. I find a combination of treatments is usually most helpful when needed. Again, sometimes you can stop at self-help and non-pharmacologic treatments. If you do need the pharmacology, I would still augment that with the other things that I mentioned. So, I would end there with just identifying and treating early and exploring all of these things that are available to you. And lastly talking with your team and making sure that they are on board and they feel that something is right for you is always good practice.

Dr. Daniel: The third and final area that the study had identified was challenges in accepting an uncertain future. And we'll just talk briefly about some skills to employ around accepting. So, here's my biggest pictorial demonstration of the difference between acceptance and non-acceptance. I don't like rain, I wish it was raining, my day would be better if it wasn't raining, my day is ruined. Every day is like this. Why does it always rain the most when I want it to be sunny? It's never going to stop. Those are that's a demonstration of non-acceptance. And what is acceptance look like? It's raining. Yep, it's raining. So, for some of us, you know, it's raining, you know, we're in a circumstance which we don't want to be in. And we can spend a lot of energy thinking about and devoted to how much we don't want to be here. But at some point, we do have to come to this decision or realization that we are going to have to accept that this is where we are. And now let's begin to put that effort and energy into moving forward and to doing what we can to be productive.

So how do we apply acceptance to real life? I just have some very basic suggestions here. First, one is called worry control. And it's a commonly used technique in psychotherapy and we really encourage people to think about the worries that they're having are they productive or non-productive? So, if

you're worried about your health, and something kind of seems a little off, and perhaps, maybe you should see your doctor, maybe you shouldn't, that seems kind of like a productive worry. You really want to think about that pretty carefully because there's something which is of concern, which has not been fully vetted yet. And that's why probably anxiety exists from an evolutionary perspective is to kind of alert us to action when something is not right.

Let's say we know something is not right. And it's already been kind of discussed and analyzed from all sides, and we just kind of ruminate about it. So that's non-productive worry. I hope my numbers are okay. Well, hoping is not really a very pragmatic strategy working towards doing all the things we need to do to keep our lab values optimal that is helpful but worrying about it, is probably not really very helpful.

Similarly, another technique is called mindfulness, which is when we kind of step back a bit from our own thoughts, and just realize that we have anxious thoughts. We're in a bit of a predicament, and there are thoughts that come through our mind that are anxious, and that's okay, and let's not overreact to them, let's not respond to them like they're an emergency. We just need to acknowledge that we're in a stressful time and that we occasionally will have anxious thoughts and if we just kind of adopt that perspective, they kind of pass a little more naturally a little more easily, without having a screaming call to action.

Finally, something called Value Based Living. If you fill your time with things that are of meaning to you, so then the things that you are not able to do, or the things that you anticipate not being able to do, will seem less significant. And I'd like to just end with a Chinese proverb that I came across that I think really kind of embodies this idea. And it's one disease long life, no disease short life. And it's an ancient proverb. And I think there are two ways of understanding it, which both are really relevant. One of them is that if you have one disease it brings our attention to our health, and it causes us to be healthy, and to pay attention to our every decision of everyday living, and people that have one disease sometimes end up exercising, eating right,

Mental Health

being as healthy as they can, because they kind of know that, in some ways, the odds are stacked against them, as opposed to people that don't have that one disease or don't know about that one disease, and they feel like they have the luxury of neglecting their health.

I think another way of understanding that is really that the one disease long life is that if you have a disease, it really forces you to contemplate what is really meaningful to you. And if you're devoting all of your resources to the things that really are of value to you, you will feel like you have a long life you will have all the time in the world to do the things that are really relevant to you. But if we never stop and take the moment to evaluate and realize that time is passing by whether we have a disease or not, life will feel very short. We'll feel like we're constantly running out of time to do the things that really are of value to us.

So here is our contact information. We both are happy to receive any questions or comments that you may have but now I'm going to turn over the Q & A portion of today to Stephanie, thank you all.

[Audio Ends] [00:40:17]