TR$_x$ANSITION Scale Answer Guide for Kidney Patients

Question	Knows a lot = 1	Knows a little = 0.5	Doesn't know = 0	N/A
1.	They say they have CKD (chronic kidney disease) or kidney failure (ESRD) and/or they can name specific cause of kidney disease: i.e., FSGS (focal segmental glumerulosclerosis), Diabetes, HIV, Hypertension, etc.	They give a general answer like "Something is wrong w/ my kidneys" or "My kidneys don't work like they're supposed to".	They have no idea	
2.	They can name physical symptoms that they experience directly related to or caused by their health condition. They may also be able to name symptoms that others may experience but they do not. Examples: **Nephrotic Syndrome or FSGS** patients – swelling, fluid retention, spill protein in their urine; **Lupus** – skin rash, joint pain/swelling. **Dialysis patients** – swelling**,** headache, high blood pressure. **Peritoneal dialysis** – Belly pain if they have an infection. **Transplant** patients have few or no symptoms.	They name generic symptoms (i.e., tired, less energy, don't feel good, flare) but they are not specific.	They do not know any symptoms or they name symptoms that are unrelated to their health condition.	
3.	They are able to name more than one way their health condition may affect their future health and they are specific. They may say "I won't be able to play football in college bc I have a kidney transplant" and "I may eventually have to go on dialysis as my kidney function gets worse".	They can only name one way how their health condition may affect their future health OR they give a general response such as "I can do more/less of what I want to do or like to do".	They are unable to report or do not know how their future health may be affected.	
4.	They are able to name all of the medicines they take for their health condition.	They are able to name some of the medicines they take for their health condition.	They do not know any of the meds they take for their health condition.	They do not have any prescribed meds for their health condition.
5.	They know when they take each of their medicines. For example, "I take lisinopril once a day in the morning and Cellcept two times a day (once in the a.m .and once in the p.m.)".	They know when they are supposed to take some of their medicines, but not all of them.	They do not know when they are supposed to take any of their meds.	They do not have any prescribed meds for their health condition.
6.	They know why they take each of their medicines. For **transplant** patients, most important ones are anti-rejection meds: Prograf, Cellcept, Cyclosporin, Gengraf, Prednisone. For **CKD or Dialysis** patients, most important ones are: phosphorus binders (e.g. calcium carbonate, renagel), Bicarbonate supplements, Iron (ferrous sulfate), Epogen or Aranesp.	They know why they take some of their medicines, but not all of them.	They don't know why they take any of their medicines.	They do not have any prescribed meds for their health condition.
7.	They are able to list consequence for each medicine. **Transplant:** Loss of kidney or rejection, end up in hospital, could die, etc. **CKD or Dialysis**: swelling, blood pressure will go up, have to go on dialysis.	They are able identify general consequences for not taking their meds, but cannot give specific consequence for each med.	They do not know what could happen if they don't take their meds.	They do not have any prescribed meds for their health condition.

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8.	They do not ever miss a full day of medicine.	They miss a full day every now and then but not regularly.	They miss a full day at least once/week.	They do not have any prescribed meds for their health condition.
9.	They do not have difficulty remembering to take their meds every day.	They sometimes have difficulty remember to take their meds every day.	They always have difficulty remembering to take their meds every day.	They do not have any prescribed meds for their health condition.
10.	They come to their appts as scheduled or they cancel/reschedule ahead of time.	They sometimes forget when their appts are scheduled and show up late or don't show up at all.	They usually don't attend their appts when scheduled.	
11.	Yes, they read nutrition labels on foods/drinks.	They sometimes read nutrition labels.	They never read nutrition labels.	
12.	They can name the diet their dr has asked them to follow: i.e., **CKD or Dialysis** low sodium/salt, low phosphorous, low potassium. **Transplant** patients do not have a diet unless they have high blood pressure which would be low sodium/salt. **Obese** patients: low calorie diet.	They know they aren't supposed to eat/drink certain things but they don't know why (can't name specific diet).	They don't know if they are supposed to follow a diet or not.	
13.	They are able to name at least 3 specific foods/drinks they are supposed to have more or less of such as fried foods, processed foods, dark sodas, chocolate, water, etc. Potassium diet – Avoid bananas, potatoes, tomatoes, oranges. If they are on cyclosporine, no grapefruit.	They can name less than 3 examples of foods/drinks they are supposed to have more or less of.	They do not know examples of any foods/drinks they are supposed to have more or less of.	They do not have a diet.
14.	They usually remember to take their meds on their own w/out requiring a reminder.	They sometimes remember to take their meds on their own, but they also sometimes need a reminder.	They do not remember to take their meds on their own and rely on someone to remind them.	They do not have any prescribed meds for their health condition.
15.	They do not need someone to remind them to take their meds.	They sometimes need someone to remind them to take their meds.	They always need someone to remind them to take their meds.	They do not have any prescribed meds for their health condition.
16.	They always call in rx refills themselves or manage them via the internet.	They sometimes call in refills themselves or manage them via the internet.	They never call in refills themselves or manage them via the internet.	They do not have any prescribed meds for their health condition.

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17.	They always pick their refills up from the pharmacy. If they do not have a driver's license, they at least ride w/ someone and are responsible for going inside to pick up their meds.	They may go w/ someone to pick up their refills, but they don't do it on their own.	They never pick their refills up on their own.	Their meds are sent via mail.
18.	They contact their health providers on their own via email or phone without help from their parent.	They sometimes contact their health providers on their own, but mostly tell their parents and let them make contact.	They never contact their health providers on their own.	They have never had to contact a provider.
19.	They are usually responsible for checking out after an appt and scheduling a f/u appt as necessary or they make their medical appts on their own via phone, email, etc, and coordinate it w/ their schedule.	They sometimes schedule appts for themselves, but mostly their parents or health providers do it for them.	They never schedule dr appts on their own.	
20.	They always perform their own medical procedures.	They sometimes perform their own medical procedures, but someone else does it for them most of the time.	They rely on someone else to perform their medical procedures.	They do not have any medical procedures to perform on their own.
21.	They know their health condition will or will not affect their ability to have children. In most cases, CKD will not affect fertility. Female dialysis patients often have a difficult time getting pregnant, but it is possible. Lupus carries higher risk for infertility in females. Fertility can be affected in males if they have been exposed to cytoxan.	They don't think they will have a problem getting pregnant.	They do not know.	
22.	They know specific risks associated w/ having their health condition and becoming/being pregnant. **CKD IV-V** – very low risk of losing pregnancy/miscarriage. **Dialysis** patients – may lose the baby early on particularly if they have Lupus. **Transplant** patients – run risk of rejecting their kidney due to being exposed to their partner's antibodies through the baby.	They are aware that risks may exist but they are unable to name them. They say there may be some problems but they are not specific.	They do not know if their health condition will cause risks associated w/ pregnancy.	Males
23.	They are able to name medicines they are currently taking that would be harmful to an unborn baby. **CKD and Dialysis** – ACE inhibitors ("prils" - lisinopril, enalapril, etc) or ARBs ("-artans", losartan, valsartan,etc). These blood pressure meds can possibly cause an unborn fetus to have kidney failure. **Transplant** – anti-rejection meds can cause pregnancy loss or having babies who are small or premature.	They are aware that they are on medicine that would be harmful to an unborn baby but they cannot specify which meds they are.	They do not know if any of their meds would be harmful to an unborn baby.	Males
24.	They report both condoms AND birth control.	They report either condoms OR birth control.	They cannot name protective methods.	
25.	They have a specific plan post-high school or college. They know they will be attending college, entering the workforce, or joining the military. They have an idea of what they would like to be or do.	They do not have a specific plan or idea. If they are in high school, they "think" they might go to college, but they haven't decided. If they are in college, they have not declared a major or identified a field of study or post-college employment.	They have no post-high school/college plans or they don't know.	

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26.	They are able to report that health insurance helps pay for (or reduce the cost of) meds, dr visits, hospital stays, labs, etc, things that are medically necessary.	They know it helps pay for "stuff" but they are not specific.	They don't know.	
27.	They are able to name their primary insurance provider.	They know they have insurance but they don't know the name.	They don't know if they have insurance and don't know the name.	They do not have insurance coverage. They are self-pay patients.
28.	For patients covered by their **parent's insurance**, they know that they are eligible to be covered until age 26, no matter if they are married, not living in their parent's home, or in school. For patients covered by **Medicaid**, they know that they can receive coverage under MIC (Medicaid for infants and children) until they turn 19yo. Once they turn 19, they will have to reapply as an adult. For **Transplant** patients, they know their Medicare coverage ends 3 years post-transplant. ***Most important knowledge is that their insurance status changes and they need to be aware of how/when this happens and who to seek information from.*	They have an idea that it may end at a certain age, but they are unsure what age specifically.	They do not know when it will end.	They do not have insurance coverage. They are self-pay patients.
29.	They know they can get health insurance coverage through their job. If their job does not offer coverage, they can buy it on their own, or they may qualify for government assistance depending on their financial status.	They say they can get coverage by looking in the phone book or internet or going to social services. They do NOT identify employment as a way to get health insurance coverage.	They do not know how to get coverage.	
30.	They report that they will be primarily responsible for taking care of their health needs. They may recognize that others can help and provide support.	They will depend on someone else to primarily take care of their own health needs.	They don't know who will take care of their health needs.	
31.	They report asking their medical provider for a recommendation/referral.	They say they will look in the phone book, on the internet, ask a family member/friend, etc. They do NOT mention asking their current medical provider.	They don't know.	
32.	They know they must sign a consent to release form in order to transfer their medical records.	They say they'll call and ask their dr to fax/send it to their new provider but they do NOT mention signing a consent form.	They don't know what they need to do or what is needed from them.	