Staff Education Session #2 for Kidney Care Clinic Staff

Transplant First: Helpful Resources, Questions and Answers

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Answers: Dr. Jagbir Gill, Nephrologist, St. Paul's Hospital

Questions in RED, answers in BLACK.

1. Can you speak a little bit about medical marijuana and transplant? And as a physician, how do you screen for addictions during the screening process for a transplant?
    - (JAG) In terms of marijuana use, it's not a contraindication to transplantation. The main thing we're concerned about is inhalational marijuana as it can create problems post-transplant in relation to fungal lung infections. In these circumstances, we advise patients to discontinue use prior to transplantation. Marijuana is certainly not an absolute barrier to referral for transplant.
    - (JAG) In terms of the broader issue of addictions, the social work assessment gives us a sense of whether a patient is actively using substances. It's a particular concern for the more dangerous illicit substances like cocaine which require abstinence. These patients are typically involved in a recovery program before being activated on the waitlist. For cigarette smoking, our policy is that we ask patients to quit smoking but we typically do not cancel a transplant because someone hasn't followed through with that. But our messaging still is that people need to quit.
    - (CAROLYN) I'll just do a quick add on in terms of the social work assessment - one of the questions asked is whether there are any formal tools that we use for addiction screening. There is not a formal tool, but it is part of what social workers explore during a screening interview. With some patients, when they acknowledge that they have an addiction issue, they're willing to receive treatment. In those cases, the team will work with that patient and give them an opportunity to deal with that addiction and then reassess them in six months or a year. That's sometimes how we'll support people but any addiction that's out of control and interferes with their life or their ability to be compliant post-transplant or interfere with their health is obviously a contraindication, would you agree JAG? (JAG – yes, absolutely.)

2. Can you review the risks to living donors re development of kidney disease and other long-term health issues?
    - (JAG) The living kidney donation should have minimal impact on the long-term health and risk of kidney disease in carefully selected individuals. What we know right now is that the act of donation does not cause kidney disease - however, having one kidney can speed up the progression of kidney disease in the event that the living donor acquires kidney disease down the road. So the goal of our assessment is to identify risk factors for potential donors to develop kidney disease. If the risk is very low, then they can proceed with donation while acknowledging that should some very rare freak event happen that we're unable to predict at this time that their risk of developing end stage kidney disease in the context of that will go up slightly. If a donor has anything other than a very low risk of developing kidney disease, we will not let them proceed. That's why we're quite conservative in terms of our eligibility criteria for donation. For those of you that like stats, there has been a comprehensive look at the risk of end-stage kidney

disease after donation in the US and the rate that we quote patients is that for every 10,000 donors, 30 will go on to develop end-stage kidney disease within 15 years. This is an exceedingly low-risk when you compare it to the general population.

- On a related note, kidney donation does slightly increase the risk of diseases such as hypertension and that is also discussed with all potential donors.

3. Why are foot ulcers a barrier to transplant?
   - (JAG) The major concern with foot ulcers, particularly open wounds, is the risk of infection. So if there's an active infection or an active area that is a high risk for infection after a transplant, that risk of infection goes up substantially when anti-rejection immunosuppressant drugs are initiated post-transplant. It is important to make sure that all wounds are healed and that any osteomyelitis or other underlying infection has been treated prior to proceeding with transplant.

4. Why require a dental assessment prior to transplant?
   - (JAG) It is similar to the previous question in the sense that it really boils down to infection risk. A dental assessment is required to make sure someone doesn't need any major dental work (e.g., large abscess) which may increase the risk of infection post-transplant. If there's something to be done, it is better to have it done pre- rather than post-transplant.

5. What are some of the factors which contribute to making the donor assessment process so long?
   - (JAG) That's a good question and an important one. There's probably a few different issues, I'll start with the ones that we have limited control over just so we understand that piece.
     - An important part of the donor assessment is giving the donor sufficient time to think through and process whether they actually want to donate or not. Many people will contact us - some are very motivated and have already made up their mind. Others are at a much earlier stage and are seeking information but have not made up their mind and need time to process the information.
     - Our policy is not to be coercive. What that sometimes leads to is inefficiency of the donor evaluation process. As an example, if someone calls and says: “yeah I'm interested in donating,” we will send them an information package which includes a health questionnaire and bloodwork. If they don't complete those things and send them back, we do not follow-up with them. The reason is because we're not sure if the donor is not doing it because they don't want to or because they just haven't had time to and it's important that we not provide external pressure to people to make them feel like they have to move forward in this process at a pace that they may not want to. So that's the piece that's hard to control.
     - Other kinds of delays include people living far away (coordination is more difficult) and delays in getting certain investigations done. There are many steps and many tests that donors have to go through and that can sometimes take a while.
   - (JAG) The problems in BC are similar to those experienced across the country. The average time that it takes a donor to get worked up in Canada is about 10 months. That's the average across all programs and is a long time. And nobody knows what exactly that number should be but people have said that a 3 month timeframe might be a good target to work toward for a motivated donor. But the key there being that it's a motivated donor.
     - From our experience, complaints about the length of the donor process are more common coming from recipients than donors. And that's a tricky one to understand because

maintaining confidentiality between donors and recipients is a key issue for us and a recipient may not have been told by the donor what's going on in their process so there may be a perception that the process is taking a lot longer than in fact it is. The latter may be because the donor is still in the thinking phase about donation but doesn't want to tell the recipient.

  - I should say that this is an area that we're focusing on right now to try to figure out. We have heard from some donors that this is an issue and so we want to try to streamline this process. We haven't fine-tuned how we're going to do that but I envision that within the next 6 months to a year, we're hoping that we'll have a process where we will potentially be upfront asking donors what they want to do – fast track versus slow process - and then that may help us expedite that.

6. Can you talk a little about the risks associated with a deceased donor kidney from someone with a high-risk lifestyle and how these kidneys are screened?
   - (JAG) This is an important question because donations from deceased donors include people who have, for example, had drug overdoses from fentanyl or other kinds of issues associated with high-risk lifestyles.
     - The basic work up is this: Every deceased donor or potential deceased donor undergoes a medical social evaluation from the deceased donor coordinator at BC Transplant. This involves getting a comprehensive history which includes sexual history, drug history and incarceration history - anything that we think is associated with an increased risk of having a transmissible infectious disease.
     - In individuals that have no known history of any of that, they get serologic testing for HIV, Hepatitis B, etc. as part of their routine work up, so everybody gets screened for those infectious diseases regardless of life style.
     - In the subset of individuals where there is a history of high-risk lifestyle or the history is unclear, additional high sensitivity tests are conducted that must be negative before we can proceed. If those tests are all negative, we will then approach the recipient and inform them that the potential donor we are proposing does have a social history with some high-risk characteristics but that given the negative test results we feel it is safe to proceed as long as the recipient is willing. The risk of transmission of infection (which is quite low) is reviewed. In these circumstances, the recipient must provide consent.
     - Now by way of process, for patients who were added to our waitlist during the past year, the discussion with the recipients about receipt of deceased kidneys from a donor with a high-risk lifestyle occurred prior to putting them on the waitlist (as opposed to having the discussion with them at the 11th hour prior to transplant). So we're explaining this to them, we're outlining the risks, giving them a document and then asking them to sign to say they consent to be offered these types of kidneys. We will still confirm their agreement at the time of transplant, but they can also declare that they do not want to hear these types of offers in which case we will not be offering them those kidneys.

7. What do you advise KCC staff to say to patients who are non-compliant with their treatment but are interested in transplant?
    - (JAG) Non-compliance, or non-adherence, is an important barrier to transplant in the sense that if a patient consistently demonstrates non-compliance with their kidney treatment and there is reason to believe this non-compliance will continue during the post-transplant period, this is a contraindication to transplantation. Having said that, it's very difficult to define non-adherence and it's difficult to not refer somebody purely on that basis.
    - (JAG) My thinking would be that if a KCC patient is actively using drugs and is not showing up for KCC clinic visits, then they're not in a state of readiness for referral. If KCC staff is unsure about their state of readiness, they can refer them and communicate the issues of non-adherence on the referral. As far as what we tell patients, we tell them that non-adherence is a relative contraindication to transplantation and that they need to demonstrate a period of adherence prior to transplant and the reason for that is that although they may not see any immediate consequences after the transplant, it will certainly lead to early graft loss if they're not adherent. I'm personally a bit of a softy when it comes to non-adherence in the sense that I view it as any other risk factor. So if someone has bad coronary artery disease and where we do what we can to maximize and then take a risk on those, I view this as really no different. The psychological problems people have, it's our job to try to mitigate that risk by having them demonstrate and try to understand the reasons for non-adherence to try to proactively help them with adherence. So I guess it is a contraindication of transplantation if we're convinced someone’s going to be non-adherent but in the grey zone cases it's worth giving patients the benefit of the doubt and referring them and helping work through those issues.

8. Could you speak a little bit about how we can educate and prepare our patients who have diabetes with what to expect post-transplant? And the issues related to type 2 diabetes and transplant particularly and also to comment on the patients who had diabetes prior to transplant surgery?
    - (JAG) That's a good question. Diabetes care uniformly becomes more complicated after transplant so I always tell patients to expect that their insulin requirements are likely to go up in the early post-transplant period. For patients who have Type 2 diabetes and are not on insulin, I often warn them that they may need transient use of insulin after the transplant. For patients who do not have diabetes but may be at risk for diabetes, I warn them that they may develop de novo diabetes after the transplant. It is important that patients have those expectations going into transplant surgery because a lot of patients may not be on a huge dose of insulin once they’re on dialysis and that will change when they have a functioning graft because the immunosuppressant medications tend to increase blood sugars especially the early period where we’re giving them steroids.
    - (JAG) It is also important to tell people with diabetes that after their transplant, we will monitor their diet and diabetes care very closely. We often consult endocrinology to manage their sugars while in hospital and again when they attend the post-transplant clinic (an endocrinologist is available to the post-transplant clinic). After the initial phase, we will work with the patient on a plan for follow-up with their primary endocrinologist close to their home. But typically we loop them through the clinic for that first period.

(Further questions from people on the teleconference line):

9. It seems some nephrologists feel quite pressured with this Transplant First initiative and we're starting to get referrals that are really unsuitable. Recently a patient was de-activated from SPH because of non-compliance.
    - (JAG) I think it's a work in progress right now. In the early stages of this my preference would be not to exclude people from access to transplantation because of workload issues but I recognize that workload is a valid issue which we have to work through. But you know there's always the option that if there's a question about a referral, they can call a transplant nephrologist directly to discuss. I'm personally happy to take questions prior to a referral going through. But I hear what you're saying - it's a work in progress and it's hard for people to try to get some of the nuances off at the get-go which is why I think we should cast a bit of a broad net to start with and over time, I envision this will get easier as everyone gets more comfortable with the process.

10. What you're saying is that we should initiate the process and go through all the steps and give you all the information then you can review it?
    - (JAG) I think it should be should be case-by-case. We have criteria and in most cases, it's pretty obvious if someone needs to be referred or not. If there's a question, feel free to contact me and we can discuss if this is a reasonable referral or not. I get emails and calls quite frequently from nephrologists across the province. This can be the easiest way to go because it doesn't require a lot of paperwork.

11. You were talking about having teeth dealt with prior to transplant – I'm wondering is there anything for those people who are on income security because they only get a limited amount of funds per year to put towards dental if they aren't covered by a health care plan that includes dental? It can be a very big cost for some people.
    - (JAG) That's a really good question. Actually it's one I struggle with because the resources are fairly limited. I know there are certain REACH clinics that dentists put on for patients who cannot afford dental work. I'm sure it's variable across the province and that's quite a challenge. I know of only a couple, I think in Vancouver, that will help in those circumstances but I'm sure there are places in the province where that option is not accessible.
    - (CAROLYN) It is a challenge also from our perspective (social work). I mean there really aren't the resources and avenues so it is something that we have to continue to try to work on because it's not an easy fix.
    - (AUDIENCE) For the dentist that does the clinic in Victoria, people have to line up on that day and they decide how many on that day they'll see, it's not by an appointment, they will only do things that need to be done at that moment so if it's an ongoing process where they would have to come back for more appointments that is not on.
    - (JAG) I think it's a really important point you raise and I don't unfortunately have a good fix off the top of my head because it is a challenge that that we all face. Now you know when push comes to shove, unless someone's got a horribly acute problem going on with their teeth, I don't view that as a massive barrier to transplantation so I don't think we would ever hold up a transplant on the basis of that. If someone's got a big abscess, we can always admit them to hospital and get the dentist in the hospital to deal with it. But it's actually a really important point you raise and as we're talking here I'm wondering if it's worthwhile for us to maybe

formally reach out to some of these clinics that exist and come up with some sort of a strategy for low-income patients. I think it's really important.
- (AUDIENCE) The kidney foundation is being sought out more and more to help with all the costs of some of these things to be able to provide for people. There are a couple conversations happening right now that might benefit from having that information.

12. Are there several points in the process where the recipients check in with their donor on whether they want to proceed?
    - (JAG) We don't advise donors not to communicate with their recipients, that's totally up to them. The donor and recipient can talk amongst themselves as much as they want - it's just that we will not provide information to the recipient about the donor. It's all designed to protect the donor and maintain their autonomy so they can go through this process in a safe way.
    - (JAG) Upfront we remind them that they can opt out at any point so that they can make the decision not to proceed in a very confidential manner and we will not provide that information to any potential recipients. We just let potential recipients know that the person is not eligible.
    - (JAG) We do have people that will inquire and then will just fall off and won't contact us any further. We don't go out of our way to contact people to say "hey, you had declared an intent to donate, are you still considering it?" We presume that if someone wants to do it, they're going to follow up with us, they have to be proactive.

13. I've had a couple of potential donors that have been very leery to start the process because they worry what the recipient may think if they get to the end and then back out. Who communicates that to the recipient? Is the donor required to have that conversation with the recipient? or is that the recipient transplant team?
    - (JAG) We leave it up to the donor to decide. So we say if you want to do it, you can do it and if you choose not to do it, then the recipient team can inform the recipient, again presuming the recipient knows what's happening with the donor.
    - If there are four donors being worked up, we don't tell the recipient that there are four donors being worked up until it's done, until we know there's someone who's going to donate because the donors may not want the recipient to know. We don't routinely tell the recipient anything about donor workups. But if the donor says, "listen, they know I'm being worked up and we need to tell them and I don't want to tell them" then we'll tell the recipient. We want to avoid difficulties for the donors in terms of their relationship with the recipient so if we can, that's why we do offer lots of alternatives to the donors to help mitigate some of that.

14. If a donor calls and leaves a message on the machine saying, "Hi I'm wanting to be a living donor for so-and-so at whatever location, this is my phone number, call me back, I want to start the process." I'm hearing from several people that they don't get a call back so should they be calling once a week for the first three months or is there some sort of thing for the donor if they get blocked in transition sort of thing or…?
    - (JAG) I've heard that every now and then as well and we've reviewed it and they should be getting the call back within a week or earlier. If they're not, then that's an inefficiency that we need to correct. If someone tells you that happened to them, then yes I would tell them if they haven't heard back in a week, then there's no harm in calling back. That's fine.

15. If the father (recipient) is age 70 or older and his daughter is around age 40 and willing to be a donor, would you allow the transplant to proceed despite the age difference? or would you tell them about paired exchange? or would you suggest to the daughter that she would not be a good candidate because her father has kidney disease?
    - (JAG) A couple of issues there, it depends on if there's a reason why that daughter couldn't directly donate to the father in terms of the kidney function issue. Now her risk of kidney disease will need to be determined just like any other donor and so it depends on the type of kidney disease the father has. Many types of kidney disease have no family hereditary component whatsoever so in that circumstance it's fine but I'll give you an example of: the father has diabetic nephropathy and then you see the daughter and the daughter has borderline diabetes and she's 40, well, obviously she shouldn't donate her kidney and we'll say you're not eligible to be a donor at all. But just by her age alone that wouldn't rule her out. Now in terms of her options, donors are given the option to donate directly or donate through the paired exchange. This is not something we've discussed routinely but it's something we're moving towards now where all donors will be given that option. It's almost a stage process - first let them get through the thinking process as to whether they even want to donate. Once they get to the point where they decide they wish to donate, then we will discuss the options with them. We don't discuss paired exchange with everybody, it depends, but generally speaking we bring up with potential donors the option of donating through the paired exchange program.
    - So the opposite scenario from what you described might be more relevant. We have in the past had patients who are age 40 and the donor is age 70 and the donor is healthy enough to donate but we say that the 70 year old person's kidney is not ideal for the 40 year old. In these cases, we suggest they consider the paired exchange program even though he/she may be compatible as a direct donor. Through the paired exchange program, the 70 year old will donate to an older person and we will try to get a younger kidney donor for the younger patient. However, the bottom line is if a donor is safe to donate after they've done their evaluation and if they want to donate directly to the recipient and there's no problem with the recipient receiving that kidney, then they can do so. Doesn't matter how old they are.

16. Why do we see from time to time a patient who is approved for a living donor when they have no living donor?

(JAG) We shouldn’t - I mean there's people who may have been approved for a potential living donor and then that living donor fell through either because something came up medically or they opted out in which case they've been medically approved for transplant but they’re maybe not yet on dialysis and that's why they're not active on the list. That’s the only scenario I can think of.