What Matters To Us – Overcoming Taboos

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There are many subjects not openly talked about in women's healthcare, but this is exacerbated as a transplant recipient. The focus tends to be on our labs and looking for signs of rejection. While I understand the importance of this focus, I also have experienced that most of my post-transplant care has evolved around other considerations which I would like to discuss and grouped in 3 categories:

Mental health: I am 55 years old and in year 14 of my kidney transplant. As I age, I know my chances of getting another transplant are reduced, whether it's my own health deterioration or the fact a younger patient will always have the priority. No one on my transplant team asks me about these feelings, yet I know I am not alone. It is always in the back of my mind "how long do I have?". I don't make long term plans because I frankly don't know if I am going to be alive or reliant on a dialysis machine. This isn't pessimistic – it's simply the reality of living with a transplant. I have the benefit of being able to afford psychiatric care but I wished mental health was of the same importance as whether my creatinine level was fine.

Another mental health aspect is survivor's guilt. While I had a living donor, I am still struck with how to honor this gift I have received. How do I show my donor that I am grateful? If I eat something I shouldn't and my labs are off, I feel like I am not taking care of my gift. When I tested positive with Covid in January of this year after being fine for 2 years during lockdown, I felt guilty. It took me several years to even call the kidney mine and that was after months of therapy. I do have the advantage of talking to my donor but I don't always share these thoughts.

My sister's donor was a 12 year old boy. Her survivor's guilt is immensely different than mine. She has shared with me she questions if he would have made the same decision if it was up to him vs his parents. She has written letters to the donor family and has never heard back so she struggles with the inability to thank them. While we go through all this evaluation to be eligible for a transplant, we are not provided the mental health support afterwards. It may occur for the first few months but then it fades away and we are left to our resources to figure it out.

A 3rd mental health item is societal pressure of what it is to be a female. My family in Canada is very traditional where a woman's value is based on how many children and grandchildren you have. I chose not to have children in my 30's after meeting a geneticist, because I learned that was one sure way to stop the PKD gene from going to another generation. I also didn't want my children to have to take care of me, like I did when I took care of my mom as a child. I have been told that was a selfish decision and as I have age, am now labeled the spinster aunt. It's amusing to me now, but it was extremely hurtful when I was younger.

Sexual health: I had been diagnosed with extensive HPV in my reproductive and colon about 3 years ago. I underwent many painful examinations and two very painful removal surgeries plus I see a dermatologist monthly due to warts on my feet. There is a stigma associated with HPV and I would get questioned about my sexual behavior. I had to remind clinicians CellCept was the root cause of my HPV. I gave up dating because I didn't want to have to explain this part of my care when a transplant was hard enough to talk about.

After being advised I needed a 3rd surgery because the HPV dyplasia came back, I refused and got second opinions. I advocated to get off CellCept and had my UCLA nephrologist, gynecologist, infectious disease, dermatologist, and oncology naturopath all work together to come up with a solution. The decision was to stop CellCept and after 6 months, all signs of HPV had disappeared. They were shocked and now, 1.5 years later, I still have no symptoms. I would have repeatedly undergone evasive painful surgery if I hadn't pushed to find another option. I am fortunate my UCLA team is all females but in 35 years of nephrology care, it's been mostly male. I never discussed my sexual health with them. I never felt comfortable to do so.

Relationship Dynamics: Finally, I would like to talk about relationships and specifically dating. I was divorced before my transplant because my ex-husband couldn't deal with my declining health. Dating post-transplant has not been easy. I tell people upfront because one can easily Google my name and read I have a transplant. I am proud of my advocacy work and yet I get told by people I shouldn't talk openly about being a recipient.

I have been asked by men if they have to donate their kidney to me if I need another one. I have had men afraid to look at my abdomen, let alone touch my abdominal scars. I've had men not be understanding about my medication schedule. Probably the worst was a man I had been dating for 3 months who asked me "how much does it cost to be with you?" My reply was that I wasn't looking to date for financial reasons. Since I was diagnosed at 19, I ensured I got educated and worked hard so the financial aspects of my medical care were never an issue. He broke up with me a few weeks later because he saw me as a financial burden. Similar to the sexual health, these interactions deter me from dating. I find it condescending to have people tell me “you just haven’t met the right man”. The reality is having a complex illness is not very attractive to most people. No one wants to admit it though, let alone talk about it.

I am not alone in any of these taboos as we talk about them behind closed doors or in our private Facebook groups. Never has a healthcare professional, especially a transplant clinician, proactively asked me. We need to change that because our transplant care is so much more than a few lab results.