Kidney Transplant Recipients' Perspectives on Cardiovascular Disease and Related Risk Factors After Transplantation: A Qualitative Study

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Background. Cardiovascular disease (CVD) is a major cause of mortality among kidney transplant recipients (KTRs). These patients have a high prevalence of risk factors, such as hypertension, diabetes, and dyslipidemia. Despite regular medical care, few of them reach the recommended therapeutic targets. The objective of this study is to describe KTRs’ perspectives on CVD and related risk factors, as well as their priorities for posttransplant care.

Methods. Twenty-six KTRs participated in a semistructured interview about their personal experience and offered their perspectives on CVD risk factors posttransplant. The interview was digitally recorded and the transcripts were analyzed using a thematic and content methodology.

Results. CVD and related risk factors appear to be underestimated and trivialized. Only 2 of 26 patients identified CVD prevention and treatment as a priority. The most important posttransplant priorities identified by patients were related to immunosuppressive drugs (13 of 26), posttransplant follow-up (15) and graft survival (9). However, 21 of 26 patients stated they wanted to be better informed about posttransplant CVD risk factors.

Conclusions. CVD and related risk factors are not a priority for KTRs, and the importance of CVD is underestimated and trivialized. KTRs did recommend that tailored information be provided by various professionals and at several points in the transplantation process. This knowledge will help us develop a new approach to increase awareness of posttransplant CVD and related risk factors.

Received 19 October 2016. Revision requested 13 March 2017. Accepted 31 March 2017.

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L.L. holds the Sanofi-Aventis Endowment Chair in Ambulatory Pharmaceutical Care and is conducting a research project funded in partnership with Pfizer Canada. This project was funded through an internal research continuum grant from the Canadian National Transplant Research Program, Canada.

F.B. participated in the data collection, data analysis, and writing of the article. J.A. participated in the data analysis and writing of the article. C.D. participated in the writing of the article. H.C. participated in the study design and writing of the article. M.-C.F. participated in the study design, data analysis and writing of the article.

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ISSN: 2373-8731
DOI: 10.1097/TXD.0000000000000679
of cardiovascular risk factors after kidney transplantation is that KTRs do not feel engaged in CVD prevention and self-management after renal transplantation, regardless of the information given on how to manage risk factors, and perhaps CVD is not a priority in their posttransplant care. In a recent Australian study conducted with kidney transplant patients, CVD was not viewed as a priority. On the other hand, CVD is a major concern for transplant professionals given the high associated morbidity and mortality. The aim of this qualitative study is to describe KTRs’ perspectives on CVD and related risk factors after transplantation, as well as their priorities for posttransplant care.

MATERIALS AND METHODS

This study was exploratory in nature and used semi-structured interviews with KTRs. The recruitment and interviews were carried out between January 15, 2015, and May 30, 2015. Convenience sampling was used to recruit patients. All KTRs attending the transplantation clinic of the Centre Hospitalier de l’Université de Montréal during the study period were approached (371 patients) by transplant nurses or receptionists with an invitation letter describing the project. To be included in the study, patients had to have a functional renal transplant (ie, not receiving dialysis treatment); understand French, English, or Spanish; and consent to participate in the study. Patients, having decided to participate, were invited to meet a member of the research team (F.B.) who has experience conducting qualitative interviews, and who was not a member of the transplant team. All but 2 of the interviews were conducted at the clinic, in a private office. Two interviews were conducted by phone. The interviews lasted around 30 minutes and were digitally recorded. The Centre Hospitalier de l’Université de Montréal research ethics board approved the study, and all participants gave their informed consent.

The issues covered during the interviews were outlined in an interview guide with open-ended questions. The questions addressed the following themes: (i) the overall experience of kidney transplantation, (ii) the definition of success and failure in the context of kidney transplantation, (iii) priorities in posttransplant care, (iv) patients’ perspectives and attitudes on CVD and related risk factors, and (v) patients’ recommendations for the transplant team to address CVD and related risk factors, and (vi) about the sociodemographic characteristics. The interview guide was pretested with 3 individuals who were not KTRs. Furthermore, the content of the interview guide could be modified throughout the study as new topics emerged from the interviews.

The interview transcripts were analyzed using the content and thematic analysis method described by Miles and Huberman. This involved (i) establishing a list of themes based on the interview guide, which constituted the coding frame; (ii) reading the transcripts and sorting them according to the coding frame to create a more abstract frame of analysis; (iii) adding new themes or categories as they emerged from the transcripts; (iv) organizing these categories into figures, charts, or matrices; and (v) drawing corresponding conclusions. NVivo 11 (QSR International) computer software was used to facilitate the qualitative analysis. An independent researcher with experience in qualitative methods and research in the field of organ transplantation (J.A.) coded 15% of the raw data, and the rate of coding agreement was subsequently assessed at 90%.

RESULTS

Respondent Characteristics

Thirty-seven KTRs agreed to participate; however, 11 of them later declined because they were unavailable for an interview. All interviews were conducted in French, except for 1 conducted in Spanish. The number of participants was sufficient to achieve data saturation (additional interviews did not yield any new information). Also, our sample featured a wide range of patient types (internal diversification) in terms of respondent characteristics (sex, time from transplantation, age, prior experience of dialysis). The KTRs who took part in this study were between 33 and 72 years of age (the average age was 54), and 54% were men. A total of 85% were white, and 73% had completed postsecondary education. Twenty-seven percent were in their first year posttransplant, and the average time since transplantation was 61.8 ± 60.8 months (median, 34.6 months; range, from 2 to 180 months). The clear majority (77%) received an organ from a deceased donor. For 88% of the patients, this was their first kidney transplant. Nineteen (73%) patients reported some CVD risk factors: dyslipidemia (7 patients), hypertension (6), history of coronary disease (6), diabetes (5), active smoking (4), physical inactivity (2), and obesity (1).

Table 1 summarizes the participants’ characteristics.

Patients’ Perspectives on Cardiovascular Risk Factors

This section reports participants’ awareness and perspectives on CVD and related risk factors during the posttransplant period. Participants were asked to share their concerns about their posttransplant care, whether they were aware of their CVD risk factors and how they felt about CVD. If the participants were unfamiliar with CVD-related risk factors, the interviewer provided examples, such as smoking, hypertension, obesity, and so on.

Overall, participants were not concerned about CVD and related risk factors posttransplant; only 2 patients identified CVD and related risk factors as an important posttransplant care priority. None of the participants mentioned any connection between renal transplantation and CVD. From the interview transcripts, 3 types of attitudes were identified among participating KTRs: trivialization, acceptance, and surprise. Some patients expressed more than 1 attitude during the interview. Table 2 summarizes these results and presents interview excerpts.

Trivialization

Eighteen of 26 patients expressed trivialization at some point during their interviews. Since 7 patients did not yet have cardiovascular problems and were among these 18 patients, they underestimated the significance of this condition. In addition, patients trusted their medical teams and believed they would be able to treat them if a cardiovascular issue were to occur. One patient (no. 17) disregarded the risks of having CVD and claimed that some disease would cause his death: “My feeling is you can’t die if you’re healthy. We’ll eventually...”
TABLE 1.
Participant characteristics

| Characteristics                  | Participants, N = 26 (%) |
|----------------------------------|--------------------------|
| Age (mean ± SD)                  | 54.4 ± 11.1 y            |
| Sex                              |                          |
| Male                             | 14 (53.8)                |
| Ethnicity                        |                          |
| White                            | 22 (84.6)                |
| Education level                  |                          |
| High school                      | 7 (25.9)                 |
| College                          | 7 (25.9)                 |
| University                       | 12 (46.2)                |
| Working                          | 14 (53.8)                |
| Family income                    |                          |
| ≤ $25 000                        | 7 (25.9)                 |
| $25 000 to $50 000               | 4 (15.4)                 |
| $50 000 to $75 000               | 4 (15.4)                 |
| $75 000 to $100 000              | 3 (11.5)                 |
| ≥ $100 000                       | 8 (30.7)                 |
| Time since transplantation (mean ± SD) | 61.8 ± 60.8 mo          |
| Median (range)                   | 34.6 mo (2-180 mo)       |
| Type of kidney transplant donor  |                          |
| Deceased                         | 20 (76.9)                |
| Living                           | 6 (23.1)                 |
| No. transplantations             |                          |
| First                            | 23 (88.5)                |
| Second                           | 3 (11.5)                 |
| Dialysis before transplantation  | 20 (76.9)                |
| Cardiovascular risk factors a    | 19 (73.1)                |
| Dyslipidemia                     | 7 (25.9)                 |
| Hypertension                     | 6 (23.1)                 |
| Past myocardial infarction       | 6 (23.1)                 |
| Diabetes                         | 5 (19.2)                 |
| Active smoking                   | 4 (15.4)                 |
| Physical inactivity              | 2 (7.7)                  |
| Obesity                          | 1 (3.8)                  |

a Cardiovascular risk factors reported by the patients.

TABLE 2.
KTRs’ attitudes regarding cardiovascular risk factors

| Attitudes      | Interview excerpts                                                                 | N = 26 |
|----------------|------------------------------------------------------------------------------------|--------|
| Trivialization | “At some point, if there’s nothing wrong with you, you don’t think about it, and the only thing you do know is that, in general, you need to take care of yourself. So, that’s my point of view, the way I feel, I don’t think about it constantly, I’m not necessarily worried about the situation every day, but I do know that it’s not just a cardiovascular problem, I think about my kidney too. I need to take care of it. We have to take 1 day at a time.” (patient no. 3) | 18     |
|                | “Insofar as we do not have any tests to undergo to know how we are doing, it mustn’t be that bad. I was never prescribed a treadmill test, I never had an electrocardiogram, or a… I was never … that’s why it must not have struck me that there was a risk, because during medical appointments problems and risks, or cholesterol tests, were never really brought up, not more than that.” (patient no. 11) |        |
| Acceptance     | “If you choose to have a transplant, you have to accept what comes with it.” (patient no. 4) | 13     |
|                | “It’s beyond my control. They’re there. What can I say? Even if I don’t agree, I could have done without it, but they’re there. I don’t have a choice. And I don’t want to make a big deal of it either. Because that’s it, it’s like that, so my God, if it happens, well, too bad.” (patient no. 24) |        |
| Surprise       | “I don’t know if I have high cholesterol. I should get it checked out. No one has ever spoken to me about it.” (patient no. 10) | 6      |
|                | “I was really surprised to read that, because it’s not something I was aware of. It’s like a little alarm going off—it makes me think about what I need to be doing more of to improve my chances.” (patient no. 6) |        |
TABLE 3.
Patients’ posttransplant care priorities

| Priorities                                                                 | N = 26 |
|---------------------------------------------------------------------------|--------|
| Immunosuppressive medication                                             | 13     |
| "What worries me the most is forgetting to take a dose of my antirejection drugs. I set alarms everywhere, because I’m a bit absent-minded. I haven’t missed a dose yet but… My graft is a precious gift and it’s my responsibility to take my meds. It’s really important for me." (patient no. 11) |
| "We’re definitely worried, because we have to take these drugs for life. And they have to be taken in the right dose, every day, at the same time." (patient no. 23) |
| Posttransplant follow-up                                                 | 10     |
| "What’s the most important thing posttransplant? It’s knowing I’ll be closely monitored. If I don’t feel well, I don’t have to worry, because I’ll get answers. It’s having access to medical staff who can listen to you and reassure you, and monitor your condition." (patient no. 20) |
| "Sometimes it’s… because when I was in dialysis we had regular follow-up with the nurses, whereas here it’s once a week. What worries me is that in the time between appointments, you can have concerns. I know that you can call but you have to wait to be… for someone to answer, because you leave a message, and have to wait for someone to call you back, whereas when I had… before dialysis we could have a quick chat on the spot with medical personnel. So that’s my biggest concern, that I may have a problem between appointments." (patient no. 6) |
| Graft survival                                                           | 9      |
| "You have anxiety, you’re scared, you ask yourself, at each blood test, ‘Hey, how’s it going, kidney—A1?”" (patient no. 1) |
| "Graft survival is definitely a top priority. You don’t know how long it’s going to last." (patient no. 16) |
| Promoting a healthy lifestyle                                            | 6      |
| "I would have like to have more sports counselling. Of course, we were told, ‘Exercise, exercise.’ They told us to be active. But active up to what point? What’s good for you? And should you push yourself, or not push yourself? Can you become an athlete, or not? What… what’s the minimum you need to do?” (patient no. 18) |
| "I try to exercise. I’m very aware that if I want my kidney to last as long as possible, I have to give it a hand. So I’m much more active." (patient no. 20) |
| Prevention and treatment of psychological complications                  | 4      |
| "I asked my doctor to refer me to a psychologist because I needed some perspective. The parameters had changed and I needed to take stock. I met a psychologist at my request. I would not have met her otherwise, because nobody would have suggested it." (patient no. 10) |
| Prevention and treatment of cancers                                      | 4      |
| "Well, we know that we don’t have strong immune systems, so I’m personally scared of catching cancer-related conditions, like skin cancer.” (patient no. 12) |
| "I’m very concerned about skin cancer, so I stay out of the sun and I always apply an SPF 110 sun lotion. I avoid going outdoors when it’s sunny, I wear big hats and I always cover my arms and legs. I’m really worried about skin cancer.” (patient no. 11) |
| Prevention and treatment of CVD                                           | 2      |
| "I had cardiovascular problems before my transplant, so it’s something I’ve been concerned about for a while. It’s not because of the transplant. I work out at least 3 times a week.” (patient no. 11) |
| Prevention and treatment of diabetes                                     | 2      |
| "That’s what worries me the most—the negative effects of diabetes on my new kidney.” (patient no. 7) |

regimen (11 patients) (including taking their medication at the right time), adverse effects (5), and polypharmacy (5). Taking the drugs as prescribed was perceived as very important to keep the graft functional. One patient (no. 2) mentioned: “Well, these are drugs we’re talking about—you always, always need to check medication, antirejection medication. You know that you can vary from the set time by 15 to 20 minutes or so, because you may not be at home to take it, but it’s really important because otherwise the graft fails, so it’s better not to fool around.”

Posttransplant follow-up care was identified by 10 patients as a priority. Five of them were concerned about having fewer medical visits over time, whereas 2 others questioned the need for some medical visits, given that it can take an entire day to get test results and see the transplant physician for only a brief period. Three patients stated that the most important aspect of their follow-up care is having privileged access to professionals who can answer their questions and reassure them. Four patients who live some distance from the transplant center were concerned about the travel involved.

Maximizing graft survival was explicitly a priority for 9 patients. Five patients were very interested in laboratory results reporting their creatinine levels, which is a marker for graft function. Patient no. 16 described this concern in the following way: “They [doctors] focus a lot on creatinine levels and drug levels in the blood. It’s always on your mind.”
Maintaining a healthy lifestyle, including proper nutrition and exercise was identified as priority for 6 patients. They saw a healthy lifestyle to prolong graft survival, not to reduce the risk of CVD. In the words of 1 patient (no. 20): “I know that if I want my kidney to last as long as possible, I have to give it a hand. So, I’m much more active.”

Another posttransplant care priority identified by 4 patients was related to psychological complications after the procedure. Even 1 patient stated that they were not informed before the transplantation about possible psychological complications and said they had to ask for support.

In terms of preventing and treating other diseases, the 4 patients for whom cancer prevention was a priority were particularly concerned about skin cancer. Two patients mentioned CVD prevention, and 2 mentioned diabetes prevention and treatment. It is worth noting that none of the patients who participated in this study identified preventing hypertension or hyperlipidemia as a posttransplant care priority.

**Recommended Approaches to Inform KTRs About CVD Risk Factors**

During the interview, patients were asked about the information provided by the transplant team on CVD and related risk factors and what could be done to improve KTRs’ awareness surrounding CVD. The main recommendation made by 21 patients was to improve communication about CVD and its risk factors. Twenty-two patients mentioned that they forgot or do not remember receiving information about CVD at any time in the transplant process (before and after the transplantation). However, 1 patient mentioned that, while on dialysis, his treating team discussed a CVD and related risk factors a lot, especially smoking for this patient: (“That, yes, they talk a lot about that [smoking] in dialysis, when you’re on dialysis—my doctor has been bugging me to stop smoking for at least 15 years. They talk about that a lot, a lot when you’re on dialysis.”) Twelve patients suggested providing detailed information tailored to each patient. Thirteen patients recommended that the information be provided at each stage of the transplantation process (before the transplant, during hospitalization and in the follow-up phase), and felt it was important that CVD-related information be included in the education they receive.

Thirteen patients also recommended adopting an interdisciplinary approach. To address issues related to posttransplant CVD, respondents believe that many stakeholders should be involved. For instance, the posttransplant nurses assigned to patients should inform them about CVD and address their concerns, while the transplant pharmacists monitoring patients’ medication should remind them about CVD and explain the role of each drug. Similarly, patients should have easy access to a nutritionist and kinesiologist for help with adopting healthy habits.

A final recommendation was to adopt a holistic approach. Five patients in this study noted that they do not want health-care professionals to focus only on their renal transplant or CVD. Renal transplantation and CVD have multisystem implications (psychological, social, economic, and medical). Table 4 summarizes these results with interview excerpts.

**DISCUSSION**

This is the first study to look at KTRs’ perspectives on CVD and posttransplant care. Our respondents’ priorities tended to be graft-centered, disregarding other medical conditions, such as CVD and risk factors, such as diabetes, physical inactivity, and hypertension. This is worrying given that CVD and related risk factors can be fatal for patients and the prevalence of such risk factors was high among participants. The respondents’ attitudes were characterized as trivialization, acceptance or surprise. These findings concur with those of Howell et al, an Australian study that looked at KTR priorities in terms of posttransplant outcomes. The latter study showed that when KTRs were asked to rank posttransplant outcomes, they identified kidney rejection and kidney failure as the most important priorities, more important even than death. CVD ranked 18th on the list of priorities. During the focus groups in this study, participants also proved to have a graft-centered perspective, mentioning risk factors, such as diabetes and hypertension, as important outcomes precisely because these are harmful to their kidney. Conversely, they did not see CVD as a dreaded outcome, because the related risk factors could be controlled. Similarly, the report of a national workshop in Australia on research priorities in chronic kidney disease also found that CVD was not a research priority for transplant patients.

This study showed that 1 priority for KTRs is immunosuppressive medication. Adherence to immunosuppressive drug regimens is strongly advised before and after transplantation to prevent acute rejection and graft loss. Also, nonadherence is considered as a contraindication to kidney transplantation. Given that immunosuppressive drugs are viewed as a priority, this might lead patients to see their cardiovascular treatment as a lesser priority, resulting in suboptimal adherence with related medications. This might also explain the low proportion of patients who reach blood pressure, glycemic, and lipid targets. A small study conducted with 49 KTRs (90% of whom were African American) showed that nonadherence to nonimmunosuppressive drugs (antihypertensive, antidiabetic, and lipid-lowering medication) (44.9%) was higher than nonadherence to immunosuppressive drugs (18.4%).

The respondents in this study claimed that they did not receive any information about CVD and related risk factors before and after transplantation, even though CVD is covered in the KTRs’ transplant center’s routine pretransplant and posttransplant counselling and is a leading cause of death after transplantation. This finding highlights the fact that information provided at this transplant center about CVD and related risk factors is not reaching transplant patients. It is true that education tools before transplantation could overwhelm patients, and patients could easily forget given the waiting period for a deceased organ transplant, which constituted most transplants for the participants of this study. Because CVD is a complication of kidney transplantation, this should be part of the pretransplant and posttransplant counselling (immediate and long-term).

Although the transplant physicians in the KTRs’ center are the treating physicians for the entire graft life and have a long-term and privileged relationship with the transplant patients, study patients mentioned that transplant professionals other than physicians might be better able to provide information on this topic. According to patients or participants, pharmacists could play a significant role in providing information. Transplant pharmacists already have a pivotal role in the posttransplant care of KTRs in this center, mostly in the first year posttransplant. They meet with patients at their
The cardiovascular health of KTRs is related to the individual's overall well-being: physical, mental, social, and spiritual. You have to adopt a holistic approach because cardiovascular health is related to all aspects of a person's life. Prevention is better than cure. Having a holistic approach means asking questions like “Are you getting exercise? How is your mood? Do you have someone in your life? What type of work do you do?”. A holistic approach—biological, psychosocial and spiritual—can certainly have an impact. 

"I guess it takes a holistic approach and philosophy. We’ve been transplanted, which doesn’t just mean we have another kidney. There’s everything that comes with it. You need good blood circulation. I imagine if we want to keep the kidney we need to make sure we have good blood circulation, a strong heart." (patient no. 20)

first visit at the outpatient transplant clinic, and 3, 6, and 12 months after transplant. After the first year of transplant, they could meet the transplant pharmacist if they need to. During these statutory meetings with patients, the transplant pharmacist reviews with them their medication, adverse effects, and therapeutic targets. They may suggest some medication modifications to transplant physicians. They therefore have an opportunity to provide advice and educate patients about CVD. However, after the first year, the frequency of medical follow-up at the hospital decreases, and there are fewer opportunities for the pharmacist to continue educating patients about CVD. After this first year, community pharmacists could play an important role. In Canada, almost all prescriptions are filled by community pharmacists (less than 0.5% of prescriptions are filled via mail order). In Quebec, Bill 41, An Act to amend the Pharmacy Act, allows community pharmacists to adjust a physician’s prescription under specific conditions. Because patients have monthly contact with their community pharmacists, it may be worth exploring whether they might be able to play a role in counselling patients and in adjusting their medications to achieve blood pressure, glucose, and other therapeutic targets.

Another factor to consider might be whether peer mentoring and peer support could be used in the prevention of CVD and related risk factors. A fellow KTR with training may have more credibility than a healthcare professional in providing information about the prevention of CVD and risk factors, such as hypertension, diabetes, hyperlipidemia, and smoking. A randomized study showed that, compared with regular care protocols and financial incentives, peer mentoring was the most effective strategy for improving glucose control in a population of African American patients. Another study showed that receiving peer support was viewed as beneficial by chronic kidney disease patients and helped them make decisions about treatment modalities. Further studies looking at the impact of peer mentoring in the field of CVD and kidney transplantation are needed.

One limitation of this study was that the participants were from a single center. As such, the results cannot be generalized to other categories of transplant patients in different settings. The youngest patient included was 33 years old; therefore, young adults who could benefit in the long term from being more aware about CVD were not represented in this study. The prevalence of at least 1 CVD risk factor is high among our participants. Patients were asked to report their CVD risk factors, but their medical records were not reviewed to verify the actual prevalence of these risk factors and check if they achieved therapeutic targets. Despite the
high prevalence of self-reported CVD and related risk factors. CVD is not a postransplant care priority and a proportion of patients were surprised at or unaware of the significance of CVD.

CONCLUSIONS

CVD, the leading cause of mortality in KTRs, was not identified by participants of this qualitative study as a priority, nor were its risk factors, such as hypertension, diabetes, and smoking. Immunosuppressive treatment, graft survival, and postransplant follow-up were identified as the most important priorities after kidney transplantation. The KTRs in our study accepted, trivialized, or were surprised by the significance of CVD. This finding shows that our transplant center’s information strategy regarding CVD has failed. We need to find new ways to inform and engage patients about postransplant CVD to increase the number of patients who reach therapeutic targets and decrease postransplant morbidity and mortality. Participants in this study highlighted the importance of multidisciplinary intervention involving different professionals, such as pharmacists, nurses, and kinesiologists. Given the new roles of community pharmacists in Quebec, there is possibly a role for them to play in helping KTRs achieve therapeutic targets. Also, peer mentoring or peer-led support, which have proven effective in improving self-management in diabetes and mental health cases, could be an intervention worth applying to the field of kidney transplantation as a means of decreasing medical and cardiovascular complications. Further studies are needed to develop and test the efficacy of interdisciplinary interventions and peer-mentoring programs aiming to decrease CVD and related risk factors. Trying to improve CVD during the posttransplant care of KTRs is of paramount importance given the high associated mortality and morbidity.

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