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# Peer Mentoring as an Avenue to Explore in Kidney Transplantation: Kidney Transplant Recipients' Perspectives on Peer Mentoring

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Background. Kidney transplant recipients (KTRs) face numerous challenges following transplantation. Given that healthcare professionals do not necessarily have first-hand experience living with or waiting for a transplant, it may be hard for them to communicate with and help patients when it comes to transplant-related issues. KTRs have experiential knowledge, which could enable them to help other patients going through similar situations. Peer mentoring involves pairing mentees with individuals who have had similar experiences, to provide training, information, and emotional support. The aim of this study was to gather KTRs' perspectives on a potential peer mentoring program. **Methods.** A total of 13 KTRs took part in focus groups between June 2017 and March 2018. The focus group discussions were digitally recorded and transcribed. The content of the interviews was analyzed using the qualitative data analysis method, including deductive and inductive coding techniques. **Results.** All participants were supportive of a peer mentoring program as it is a convenient and userfriendly way to address posttransplant concerns. Peer mentoring was also viewed as a way to communicate with other patients who have gone through similar experiences and relieve the loneliness and isolation some participants experienced subsequent to their transplant. Young female participants expressed a need to connect with other young, female transplant recipients to be able to discuss issues such as pregnancy, sexuality, and body image. Conclusions. KTRs who participated in this study expressed a need for the development of a peer mentoring program to help other KTRs face the medical (including cardiovascular disease), social, and psychological challenges associated with kidney transplantation. The results of this study are the first step in the development of a structured peer mentoring program at the kidney transplantation clinic.

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# INTRODUCTION

Kidney transplantation is associated with multiple challenges for patients. <sup>1,2</sup> After transplantation, patients and caregivers have to deal with the uncertainty of future outcomes, immunosuppressive drugs and related adverse effects, psychological and medical complications, emotional distress, fear of losing or rejecting the organ, and grief or guilt for the deceased organ donor. <sup>3-5</sup> Moreover, organ transplantation is associated with changes in personal identity. <sup>6-8</sup> Healthcare professionals do not necessarily have first-hand experience living with a transplant; it may be hard for them to communicate with patients regarding certain kidney-transplant—related issues. For some patients, it might be easier to discuss certain concerns with other patients who share the same experience. <sup>9</sup>

Peer mentoring involves pairing mentees with individuals who have had similar experiences to provide training, information, and emotional support.<sup>10</sup> Peer mentoring could improve patients' management of chronic conditions, and its use has been reported for conditions such as spinal cord injury,<sup>10</sup> diabetes,<sup>11,12</sup> mental health,<sup>13,14</sup> and breastfeeding.<sup>15</sup> Peer mentoring has been found to improve patient empowerment<sup>10</sup> by enhancing autonomy, self-efficacy, and self-management skills.<sup>16</sup> Peer mentoring is also a way to have access to

1

hard-to-reach patients, such as those from ethnic minorities or living in rural environments.<sup>17-19</sup> Peer mentoring could also have psychological benefits for mentors, such as increased feeling of well-being, self-esteem, self-efficacy, and improved quality of life.<sup>9,20-22</sup> The objective of this study was to explore kidney transplant recipients' (KTRs) perspectives on peer mentoring.

#### **MATERIALS AND METHODS**

This study was exploratory in nature, and we conducted focus groups with KTRs. We used the consolidated criteria for reporting qualitative studies checklist.<sup>23</sup> The convenience sampling technique was used.<sup>24</sup> Participants were recruited from the Centre Hospitalier de l'Université de Montréal (CHUM) kidney transplantation clinic in Montréal, Quebec, Canada. Announcements about this study were posted in the clinic and flyers were distributed to 1088 KTRs attending the kidney transplant clinic from May to October 2017. To participate in the study, KTRs had to be 18 y or older and understand and speak French. Forty-three patients interested in participating were contacted by the research assistant (F.B.G.); this individual had no clinical relationship with the KTRs. After this initial contact, 8 patients refused to participate due to the travel time to come to the research institute (3), work schedule (2), a change of mind (2), and medical reasons (1). Thirty-five patients were still interested in participating after this initial contact; however, 15 patients did not participate because the timing of the focus group was not convenient for them. The timing of the focus group was determined based on a survey of researchers' and participants' availabilities. Twenty participants were supposed to take part in the focus groups (5 for the first focus group, 6 for the second, and 9 for the third), but 7 canceled at the last minute due to a personal emergency, motor traffic, a health issue, or a work problem. Therefore, 13 took part in a focus group (3 for the first focus group, 6 for the second, and 4 for the third).

The interview grid for the focus groups was based on the results on a review of literature on peer support and peer mentoring. The interview grid was developed by the 2 principal investigators (M.-C.F. and M.-P.P.). The following themes were included in the interview grid: (1) experience in helping or being helped by other patients; (2) content of a potential peer mentoring program; (3) the role of a peer mentoring program in the prevention of cardiovascular disease; (4) recommendations for a peer mentoring program; (5) facilitating factors and barriers to the implementation of a peer mentoring program; and (6) a sociodemographic questionnaire. Focus groups were conducted at the Centre de Recherche du CHUM (CRCHUM) between June 2017 and March 2018. Each participant received compensation for time and travel (CAN\$20). The CHUM Research Ethics Board approved the study (CHUM 17.009) and participants provided informed consent.

During the focus groups, participants were welcomed by the research assistant who contacted them (F.B.G.). The focus groups were facilitated by the 2 principal investigators (M.-P.P. and M.-C.F.) who have experience in qualitative research and in conducting focus groups. One of the researchers (M.-C.F.) was known by some KTRs given that she is a clinician on the CHUM kidney transplantation medical team. However, because patients are followed by all the transplant physicians

at the transplant clinic, M.-C.F. was not necessarily involved in the clinical care of the participants. The other researcher (M.-P.P.) was unknown to the KTRs who participated in the study, so she led the discussion during the focus group to minimize the influence of a clinician's presence. It was made clear from the beginning of the focus groups that what would be addressed would not impact their clinical care. The focus groups began with a brief introduction of each participant, followed by a presentation made by M.-C.F. and M.-P.P. on peer mentoring and the objectives of the study. Participants had the opportunity to ask questions on this presentation. Following these short presentations, the discussion started. All participants were invited to freely express their opinions and perspectives. The research assistant (F.B.) took notes during the focus groups. All discussions were digitally recorded and transcribed. The focus groups lasted between 90 and 135 min.

The focus group transcripts were analyzed using the content and thematic analysis method described by Miles and Huberman.<sup>25</sup> This involved (1) establishing a list of themes based on the interview guide, which constituted the deductive coding frame; (2) reading the transcripts and sorting them according to the coding frame to create a more abstract frame of analysis; (3) adding new themes or categories as they emerged from the transcripts (inductive coding); (4) organizing these categories into figures, charts, or matrices; and (5) drawing conclusions. The Nvivo 12 (QSR International) computer software was used to facilitate the qualitative analysis. A research assistant (F.B.) with experience in content and thematic analysis conducted all the coding. An independent researcher with experience in qualitative methods and research in the field of organ transplantation (A.A.) coded 100% of the raw data, and the rate of coding agreement was subsequently assessed at 95% and disagreements were discussed. The transcription of the focus groups was not sent to participants for approval.

## **RESULTS**

## **Participants' Characteristics**

Seven men and 6 women participated in this study. Nine participants described themselves as Caucasian and 3 were from different origins (2 from the Middle East and 1 from Asia). Nine participants had college- or university-level education. Eight patients received a deceased donor transplantation, 9 patients had hemodialysis treatment before transplantation, and 4 received a preemptive transplant. KTRs who participated in this study had their transplants for varying lengths of time (average 7 y, range 3 mo to 21 y). Three of them were transplanted in the year before the study, 3 were transplanted between 1 and 3 y before the study, 2 between 3 and 5 y, and 5 more than 5 y before the study (12, 13, 18, 19, and 21 y since transplant). Table 1 summarizes participants' characteristics.

# **Experience of Being Helped or Helping Other Patients**

All KTRs who took part in this study were supportive of the development of a peer mentoring program. Many of them had experience in providing information or helping other patients on dialysis or posttransplant in an informal way. However, only 1 was a peer support volunteer for the Kidney Foundation of Canada. Learning from other KTRs' experiences, helping to manage uncertainty related to kidney transplantation, viewing KTRs as a source of experiential

# TABLE 1.

#### Participants' characteristics

Characteristics	n = 13
Sex	
Male/female	7 (53.8)/6 (46.2)
Age (n = 10)	$52.3 \text{ y} \pm 11.6 \text{ y}$
Ethnicity	
Caucasian	9
Middle Eastern	2
Asian	1
Unknown	1
Employment status	
Employed	8
Retired	5
Level of education (n = 12)	
Primary school	1
High school	2
College	4
University	5
Household income ( $n = 12$ )	
<\$50 000	5
>\$50 000	7
Type of transplant	
Deceased donor	8
Living donor	5
Time since transplant	$92 \text{ mo} \pm 92.57 \text{ mo}$
Hemodialysis before transplant	
Yes/no (preemptive transplant)	9/4
Waiting time for transplantation	
<2 y	8
>2 y	5

knowledge, and the opportunity to help and support other patients were the arguments in favor of a peer mentoring program.

"It's true that as transplant recipients, we have many years of experience with whatever a person's going through, especially regarding the disease, and other people's disease, which may be less severe or more severe, or how situations compare." (woman FG2)

Table 2 summarizes the themes and presents interview excerpts.

#### **Content of a Peer Mentoring Program**

Posttransplant complications and the adverse effects of immunosuppressive drugs were identified as topics that could be discussed with peer mentors. For example, 1 participant mentioned being cautioned about diarrhea after transplantation, but he did not know at what point he should worry and after how many loose and watery stools during a 24-h period he needed to consult a physician. Unexpected fatigue after transplantation was also mentioned as an issue that could be discussed between mentors and mentees.

"You can't scare them, but they (KTRs) still have to be aware that their life has just changed. And that's what I personally hadn't realized. Yes, I was tired. (...) I think that the fatigue doesn't show so much in my eyes, but I'm very aware that I get exhausted very quickly. Before the transplant, I was always playing sports." (woman FG1)

Loneliness and the feeling of isolation after transplantation were also mentioned as topics that a peer mentor could discuss with a KTR. While on hemodialysis, participants felt supported by other patients and healthcare providers. After transplantation, they mentioned having fewer interactions with the medical team and other transplant patients.

"In dialysis, you have more support, because you're always there—3 times a week, 4 hours every time—so you have time, and everyone is talking about it. When you have a transplant, you're more isolated. At first, it's hard. That's when the transplant has priority. And as soon as some new little thing happens, whoa, you start getting all stressed out..." (woman FG1)

Another theme mentioned by the participants was logistical and practical issues for KTRs when traveling, such as jet lag and medication, and which countries are safe to travel for KTRs to minimize the risk of infection. Last, during 1 focus group, young women mentioned that they would have appreciated sharing age-related issues, such as pregnancy, dating and sex life for KTRs, as well as career development with other young adult women. Table 3 summarizes topics and presents interview excerpts.

# Role of a Peer Mentoring Program in the Prevention of Cardiovascular Disease

When questioned about the potential role of a peer mentoring program in the prevention of cardiovascular disease, participants envisioned 2 roles for this program. The first role would be to inform other patients about cardiovascular disease and related risk factors after transplantation. Most participants were not aware that cardiovascular disease was associated with posttransplantation mortality.

"The cardiovascular risk for me is a stroke. And I'm like 'c'mon, I'm 28 years old... I'm not gonna have a stroke!' But that's being in a bit of denial. Maybe getting testimonials from people to whom this has happened, you know, to cross-check and to say, 'That won't happen to me.' [...] Why am I more at risk than if I had a transplant, is it this drug that's affecting me? I don't know..." (woman FG2)

Another role of peer mentoring would be to help adopt healthy lifestyle habits. One participant mentioned that other patients could help them modify their diet and share low-fat and low-salt recipes. Peer mentoring could also help encourage patients to be more active and to pursue physical activities. Also, a participant mentioned not knowing which sports she could play because she was informed that she could not go back to the sports she used to play before transplantation as they were contact sports and there were risks for the renal graft. A peer mentor could have helped her identify sports that are appropriate for KTRs. Table 4 summarizes the role of peer mentoring in the prevention of cardiovascular disease and presents focus groups excerpts.

# KTRs' Recommendations for a Peer Mentoring Program

When participants were asked to make recommendations for the development of a future peer mentoring program, they mentioned that peer mentors should be adequately trained on empathy, communication techniques, and confidentiality issues. They also mentioned that peer mentors have to be informed

# TABLE 2.

#### Reasons for supporting the development of a peer mentoring program

#### They want to learn from other KTRs' experiences

- I would have liked for someone to come during the day and talk to me a bit about the transplant, what it does! (woman FG1)
- But also to compare ourselves... What's it been like for you? Mutual sharing, you know. And it's true that transplant recipients, more or less like myself, are not all able to handle high amounts of stress. That reassured me. (woman FG2)
- You talk, you listen, you learn about other people's experiences. Like, for the past year or 2, people are sharing experiences about travelling abroad to donate their kidney while their spouse gets a kidney from here. I find that very interesting. That's why the duration of dialysis is shorter. (man FG3)

#### Peer mentors could answer patients' questions and help manage uncertainty related to kidney transplantation

- Well, a good thing would be if there were a patient who could help us understand all this uncertainty. (woman FG1)
- So I was telling myself, if there were someone who could maybe explain to me, then it would maybe be better. (woman FG2)
- You see, that would be one thing, with others... For me, I'm at the point where I never know if it's just me getting older or the medications. (man FG3)

#### KTRs are a source of experiential knowledge

- You're more comfortable with people who are in the same boat you're in. (man FG1)
- And then I found myself alone in the hospital room. I would have liked to have someone to talk to, because, you know, I suddenly starting shaking. [...] I would have liked for someone to come during the day and talk to me a bit about the transplant, what it does! (man FG3)

#### Peer mentoring is an opportunity to help and support others

- For me, it's a feeling of... how can I explain it? The feeling that you're helping someone, you know, the feeling of doing good or of giving back to someone, that's what I find... Like a big brother. (man FG1)
- It's true that it would be good to be in touch with other people who have had a transplant, as we were saying in the group. Mutual help. Now that's important. (man FG2)
- Well, I listen to them, and I suggest things. I enjoy it, the more I do it, the more it makes me happy. (man FG3)

#### TABLE 3.

#### Topics that peer mentors could address

#### Posttransplant complications and adverse drug effects

• They warn you about that right? Diarrhea, after so many days, you call, you're in a rush, but you know, for them, what is diarrhea? Semi-liquid, fully liquid, it's liquid only...? You know? So what happens is that at the beginning, you're nervous, you're always thinking that you're losing the organ... It's difficult at the beginning. That's when the transplant has priority. And as soon as some new little thing happens, whoa, you start getting all stressed out, and then, well.... You exaggerate everything! You can't always have the answers right away... (man FG1)

# **Fatigue**

- You can't scare them, but they (kidney recipients) still have to be aware that their life has just changed. And that's what I personally hadn't realized. Yes, I was tired.
   (...) I think that the fatigue doesn't show so much in my eyes, but I'm very aware that I get exhausted very quickly. Before the transplant, I was always playing sports.
   (woman FG1)
- But there is also the fatigue, which is very present, and I think you have to remember to say it, because people... You know, you have the feeling that, "Hey! I've had a transplant, I have a new life! Let's go!" And it's so not true... [laughs] It's like "no, no, no, watch out, whoa, slow down, it's not true..." Yes, you had a transplant, you have a new life, but take it one step at a time, because your battery is going to burn out very, very quickly. But that you find out by yourself, when you get back home. You're like, "God damnit, I'm already tired!" (woman FG1)

# Feeling of loneliness after kidney transplantation

• But all this to say that when I had my transplant at 21 or 22, I felt very much alone for a very long time. (woman FG2)

#### Logistical and practical issues related to traveling

- But for travel, too. It would be important for me to get some information... I can ask 5 doctors, and they're all going to tell me different things. But you know, I see others and I say to them, "Could I take a trip?" [...] Now I'm thinking, we're getting ready for spring, what should we do? Where should we go? Can I go to Costa Rica? I don't know. Who's going to tell me that? Is there any danger, what hotel can I go to, will I have to do my own grocery shopping, and is it hygienic, is it sanitary, or I... You know? It's stressful to go on a trip, which makes me... I'm thinking, "I'm missing this." For me... (woman FG2)
- That's it! Are you better off going to Mexico or Guadeloupe or Cuba, you know, if you want to go south.... Or to Florida... (woman, FG 2)
- If there's something patients need to hear, it's that just because you get a transplant it doesn't mean you stop travelling. But small details like, OK, but when you have to change your medication, you need this and that...(woman, FG 1)

# Age-related issues such as pregnancy, living with an illness, career development

- But I met 2 girls about my age who provided me with an example [...] It's important for me not to weigh 300 pounds, to watch what I eat, to feel sexy, and to feel that I am attractive. (woman FG2)
- I don't think it's the same life issues, you know. I needed to talk about... "Would YOU take the risk of having a child after a kidney transplant? What's your reasoning?
  Would you take the risk of travelling, would you go to Thailand? What do you think? Do you find it difficult... How do you tell a guy that you've had a transplant?" Young people's issues... (woman FG2)

about the limits of their intervention; for instance, it is not the peer mentor's role to provide advice on medical treatment or to become overly involved in mentees' problems. Some participants were concerned about possible misinformation without a proper intervention framework for peer mentors.

"I think that misinformation is the greatest danger we face, and that's why I was telling myself that if we play the role of a mentor, we have to be ourselves, that we warn ourselves that we don't have to talk about things that we have intuition about but no training on." (man FG3)

Others wondered what they would do if patients told them confidential information that would be useful to the medical team. Participants also discussed the design of the peer mentoring program. Most of the participants felt that

# TABLE 4.

#### Role of a peer mentoring program in the prevention of cardiovascular disease

#### Raising awareness and informing about cardiovascular disease and related risk factors

- Out of 5, what's the priority.... Cardiovascular. It's like a 6 or 7! [Laughs] (woman, FG2)
- Well, that's new, as I said, I didn't know that until last week. I was never told about cardiovascular risks because I was a transplant recipient. (man FG1)
- Once the medication is stabilized, the stress disappears. That's the time to start talking prevention, and to say, "OK, in terms of cardiovascular care, exercise is going to be important moving forward..." The possible risks associated with that, cholesterol, all of that. (man FG1)

#### **Healthy lifestyle habits**

- At least you can explain that it's normal, and that we'll try to establish [habits] as quickly as possible. I know, you're tired, but at the very least, just like I suggested to my mother-in-law who didn't want to, "Come, let's go for a walk, we'll go at your pace. You're tired? We'll stop, we'll take a break." It would have been nice to have someone to do that, because... (woman FG1)
- It takes others to motivate us sometimes. For instance, I would have liked to have cooking workshops with a chef whose recipes use less fat and less salt. Cooking is easy when you have a salty broth, a salty roux, and salty sauces, it's very easy to make it taste good. But making a Thai stir-fry without adding salt, that's just not edible, you know? (woman FG2)
- I would have liked to have access to that. There are more and more now, you know, there's Kilo Cardio that offers a few suggestions. But I personally would have liked that, for example, let's say you arrive at the transplant clinic and instead of listening to everyone's sob stories, you say "Oh! Great, there's a nutritionist at noon..." You know, everything's long and boring at the transplant clinic, but if you know that "at noon, there's going to be a nutritionist who will make a macaroni..." I don't know, I'm just saying! [laughing, agreement]. Because they have kitchens in occupational therapy, there's one for sure. We could have done that as a group. (women, FG2)
- She wanted to know about the diet, and what she needed to pay attention to, stuff like that. And if there were any handbooks... And I know they exist, but I don't know why so few are published, I really don't know, but there are tools. (man FG3)

peer mentoring should be aimed at new KTRs, either during kidney transplantation hospitalization or during the first-year posttransplantation. Some participants mentioned that it should be offered after the first 3 mo, given that KTRs have frequent follow-ups and medical appointments in the initial 3-mo period. One participant mentioned that mentoring could be offered pretransplantation to better educate the future KTRs. This program could take different forms according to participants: individual or group meetings, phone calls, or online interactions. They mentioned the importance of involving the medical team in the peer mentoring program. Table 5 summarizes these recommendations and presents interview excerpts.

# **Facilitating Factors**

The following facilitating factors were identified by KTRs. First of all, for some participants, it could be important to match peer mentors with mentees who share the same life experiences. This appeared particularly important for young female KTRs to share thoughts on sexual life, pregnancies, and career development.

"When I had my transplant at 21 or 22, I felt very much alone for a very long time. They were all elderly, there were almost no young people, and you're in such denial about what's happening to you that you don't want to identify with sick people, and especially not elderly people... [...] I didn't realize how much I needed to talk to someone with whom I could identify. [...] So, I used Facebook, and the transplant clinic put me in contact with another transplant recipient, a woman around my age, who's a nurse, and when we met, it was like a miracle for us, because... We had the same issues, the same psychological issues, the same fears, the same sense of loss. You know, we really connected." (woman FG2)

Another facilitating factor would be that either individual meetings with peer mentors or peer mentoring activities occur at the outpatient kidney transplantation clinic. Some patients mentioned that they spent a lot of time at the clinic waiting to get their laboratory results and for seeing the physician. This

time could be used for peer mentoring activities. And, the last facilitating factor was leadership from patients and healthcare professionals to implement a peer mentoring program.

#### **Barriers**

Different barriers to the implementation of a peer mentoring program were also identified. One of them is the language barrier that could prevent some KTRs from having access to peer mentors given that KTRs enrolled in our transplant program are from different ethnic backgrounds. Another barrier identified was the location of peer mentoring activities. Some patients mentioned the absence of space at the outpatient clinic for this type of activity. They also questioned if there were any space available and appropriate for this at the hospital, raising the issue of patients from outside Montréal. For these patients, it could be difficult to come to peer mentoring activities given the distance between their homes and the hospital. Some participants mentioned that telemedicine should be explored to tackle this issue. Some KTRs even raised the issue that peer mentors should be retired patients who have time to engage in peer mentoring. For some KTRs, it would be hard for full-time working KTRs to be peer mentors. Some participants also mentioned how potential conflicts between peer mentors and the medical team would be treated. Table 6 summarizes the facilitators and barriers and presents interview excerpts.

#### **DISCUSSION**

KTRs who participated in this study largely supported the idea of developing peer mentoring because they want to hear about other experiences. They acknowledge that KTRs have experiential knowledge that healthcare professionals do not and that other KTRs could help manage the uncertainty related to the disease. Peer mentoring was also envisioned as a way to raise awareness of cardiovascular disease and the related risk factors and to educate KTRs on how to adopt healthy lifestyle habits. In addition to cardiovascular disease prevention, peer mentors could address other topics with

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# TABLE 5.

#### Recommendations for peer mentoring program

#### **Training**

#### **Empathy**

- But not just theoretical training about what a helping relationship is, or what an intervention in a crisis situation is. (woman FG2)
- If someone wants to help me, that's fine, but no sympathy. (man FG2)

#### **Communication techniques**

- Active listening, a helping relationship, I guess to a point so we can identify if someone is depressed and hiding it, well, if we get some training and we just talk. (women FG1)
- So, I don't know if training can be provided to mentors who'll be reaching out, because, in my case, the person I spoke with wasn't... No, it was rambling, he talked
  about his job, his kids, but not enough about his transplant experience, before, after, during... It was a lot of rambling, I didn't find it interesting. (man FG3)

#### **Confidentiality issues**

- Because there's a good deal of trust established, so he's comfortable revealing something to you, and you're just like... (woman FG1)
- Right, confidentiality... There are those who don't understand the notion of keeping something to yourself and... Don't have the same notion of what should be kept private, for themselves and for others. (woman FG2)

#### Limits to their potential intervention

- Someone who gets too attached, and who calls you for everything and nothing! You know, you're... He thinks you only have him to deal with... Umm, it's hard... It's hard to manage, how do you explain that to him, well... (man FG1)
- We all have limits, in fact, we need some training, we have our limits, and the part that scares me is maybe getting too involved in the person's problems. (woman FG2)
- I don't think there's any danger as long as we leave the treatment aspect out of it, [...] but it always depends on us having the judgment to know where to draw the line. (man FG3)

#### **Risk of misinformation**

Once, while in the waiting room, I overheard a transplant recipient tell a newly transplanted patient how to take her medication, you know, so I just looked at her and she said, "Oh, I think someone here doesn't agree with what I'm telling you..." But, it's because... is it really your place to tell her that, to tell her how to take her medication? No, that's her doctor's job, you know, like "try taking this one first, and then that one...," but not you as a patient, because you may take them like that, but as far as that patient taking the medications the same way, well... (man FG1)

#### Design of a peer mentoring program

# **Timing**

- Just before the surgery: I would have liked for someone to come during the day and talk to me a bit about the transplant, what it does! (man FG3)
- During the hospitalization: But I think it would be good if the initial contact were made at the hospital, because if they have more medical questions about their
  condition, the nurses and doctors are there to answer those questions, that we have... Well, look, I don't know about that! (man FG1)
- When KTRs are at home and their condition stabilizes: When they get out of the hospital, it's not a good idea right away. Me, I think I'd put it off for a while, maybe
  after 3 mo because we're so closely monitored anyway, we have so many things to... It's not the time to talk to someone really. (man FG3)
- Once the medication is stabilized, the stress disappears. That's the time to start talking prevention, and to say, "OK, in terms of cardiovascular care, exercise is going to be important moving forward..." The possible risks associated with that, cholesterol, all of that. (man FG1)

#### Individual face-to-face meeting

- Maybe meet you in person, to go for walk together; I don't mind if it's just one person. (woman FG1)
- Making a phone call is very easy, but meeting face-to-face, yes, that's better, but the issue is where, in what location, at what time... That takes much more planning.
  (man FG1)
- I think it's case by case. Each patient could have the choice of saying, "I want to meet with someone, I'd like to meet with someone my age, whose experience is similar
  to mine..." And another person could say, "It makes no difference..." (woman FG2)

# **Group meetings**

- Yes, groups that share a common interest. (woman FG2)
- Of course, information and training are never wasted. And being in a group is even better, because everyone shares their experiences and that's always better. (woman FG2)
- Maybe make a small group with everyone and re-explain that we need to be careful, that we're at greater risk of disease, more susceptible... A quick reminder would be good, I think. It would be a good thing. (woman FG2)
- Maybe make a small group with everyone and re-explain that we need to be careful, that we're at greater risk of disease, more susceptible... A quick reminder would be good, I think. It would be a good thing. (man FG3)

#### Phone calls

- Yes, just a quick hello... A phone call is very easy to do. (woman FG1)
- You spoke of mentoring, of discussion groups, but also like a crisis line [Aide, J'écoute]... [...] A hotline. [...] I know that there's S.O.S. J'écoute... A 911 for kidneys, you know! [...] 1 800 KIDNEY! (women FG2)

#### Web platform

- But it could also be a program like that, for newly transplanted patients... You know, a virtual nurse who explains the medications. (woman FG1)
- Or having a website, or... We don't have to travel anywhere! / Yes, a Web platform is needed, that's for sure... (woman FG2)
- But I think, if you pair people up or form small groups of 3 or 4, you can do it by text, in the evening, or by WhatsApp... "I got my creatinine result, I wanna give up today!" "Oh no, it's OK, it's good...." You know, hemo at 100, and you know how tired I am... "Ah, but I was in the same boat last week," you know... OK, so I'm not alone! (woman FG2)

#### Involvement of the medical team

- For me, I imagine being teamed up with a clinician, or with someone from the healthcare staff, something like that. Not alone... (man FG1)
- I think there needs to be support from professionals. (woman FG2)

# TABLE 6.

#### Facilitators and barriers to a peer mentoring program

#### **Facilitators**

#### Matching peer mentees and mentors

• I don't think there's a textbook profile, because there has to be some sort of match with the newly transplanted patient [...] If the patient who just had a transplant has the same profile as that person [the mentor], well then it's like, OK, we understand each other, we're going through the same things, our lives are very similar. (woman FG1)

#### Peer mentoring during outpatient clinic

- It may be possible on clinic days, that's when you meet the most people. There are more people on those days.
- And they often have to wait around... (man FG1)
- We'd also regularly see each other when we had doctor appointments. We'd meet often, and we'd talk with other people around us, and... I think that may also be
  a good time, maybe... You know, in the waiting room. (man FG3)

#### Leadership from patients and healthcare professionals

 There has to be a leader, positive leaders, you know. I don't think it matters if the positive leader is a patient or a healthcare professional, it can't always be the same person. (woman FG2)

#### **Barriers**

#### Language

 Access, in terms of... We talked about mother tongue earlier, like people who don't speak French, who aren't able to express themselves, and who are members of another group, for example, another group, another nationality... I keep thinking about Indigenous people! (woman FG2)

#### Location of peer mentoring activities

• Yes, but where do you do that, in which location? Are there enough offices...? That's another thing... And you also don't want to disturb anyone, the staff who are working! So that means there may also be an issue of space... (FG1)

#### Accessibility

- But even, I don't know, maybe this lady here, who's not from Montréal, who lives a bit far, well, going to a transplant centre is like a major event in her life or a big deal, whereas for me, I'm 15 km away, that's almost next door... You know, if you're in the same neighbourhood or region of Quebec, or maybe even regional, that may be... You're not the only one from some Quebec region that I don't know! Abitibi, I don't know... (woman FG2)
- But there are people who don't even have Internet... They don't have email... (woman FG2)

# Peer mentors' availability

- Who don't work, who have time... (woman FG1)
- Well, maybe there wouldn't be as many volunteers... It's time consuming, like it or not... (woman FG1)
- It takes a lot of people... I would have to stop working and dedicate myself to that, you know... (woman FG2)

## Conflicts between mentors and the medical team

• The other team members, from either the hospital support or the home support team. There may be conflicts with the person who comes to lend a hand, you know...

That's another type of potential conflict... (women FG1)

KTRs such as posttransplantation fatigue and complications, the feeling of loneliness and age-related issues.

There are few reports of peer mentoring in transplantation. Wright et al<sup>27,28</sup> have reported a formalized mentorship program for transplant recipients. The goal of this program was to give transplant candidates and their caregivers the opportunity to meet other transplant recipients or partners trained to provide support and information. All mentors received a 1-d training session on interviewing skills, support interventions, and communication and identification of red flags. Mentors and mentees were matched according to demographic characteristics such as age, gender, and marital status. During mentorship, the mentors were supported by the healthcare team. Wright et al<sup>27</sup> assessed this mentorship program with heart transplant recipients. The heart transplant mentees mentioned that this mentorship program was useful and helped them cope with transplantation. The most frequently discussed topics were medical, such as postoperative complications, medications, being on the transplant waiting list and the heart transplant surgery itself. Psychosocial issues were less frequently discussed between mentors and mentees. Our participants also mentioned that medical issues, such as post kidney transplant complications and immunosuppressive drugs, were important topics to be addressed during a peer mentoring program. However, they also mentioned post-transplant fatigue, healthy

lifestyle habits, feeling of loneliness, logistical and travel issues, and gender- and age-related issues (such as pregnancy).

Over the years, the Kidney Foundation of Canada has also developed a peer support program for patients with kidney disease, living kidney donors and transplant recipients.<sup>26</sup> The mentors are volunteers who receive formal training from the Kidney Foundation of Canada. Individuals interested in receiving peer support should make a request through the Kidney Foundation of Canada, which is responsible for matching mentors and mentees. One of the focus group participants was in fact a peer volunteer in this program. That being said, this program did not reach all patients who needed it given the strong appetite of our participants for the development of a peer mentoring program. Brunier et al9 have conducted interviews with volunteer mentors who completed the training provided by the Kidney Foundation of Canada, with the results showing that mentors benefited in terms of personal growth and psychological well-being. Jerson et al<sup>20</sup> have also revealed positive impacts for pediatric and young adult liver transplant recipients who were peer mentors and engaged in peer support with pediatric liver transplant recipients.

Another study conducted with chronic kidney disease patients and their caregivers in the United Kingdom showed that participants were supportive of a formal peer support program because peer support was a way to learn about the

future progression of their disease and the coping skills needed and was useful for validating personal feelings.<sup>29</sup> They wanted the mentor to play a role model, without being pitiful. In addition, conversations during peer mentoring were considered to be between equals, with an emphasis on emotional and lifestyle issues. During this study, participants identified barriers to engaging in peer support as a mentee, such as professional judgment (of not being able to manage their condition), lack of social skills, fear of being a passive recipient, and timing of peer support during their illness trajectory.<sup>29</sup> None of these barriers were mentioned during our study. All the obstacles to engaging in peer mentoring were related to logistical issues, such as location, mentor's availability, language barrier and potential conflicts between the mentor and the professional team. It would be interesting to explore in further detail the barriers to engaging in peer support.

There are also some reports of peer support interventions in the field of cardiovascular disease and prevention.<sup>30</sup> A recent meta-analysis looking at the effects of peer support interventions on cardiovascular disease among diabetic patients showed that these interventions were associated with a small but statistically significant improvement in blood pressure among adults with diabetes.31 Peer support interventions were also developed to encourage a Mediterranean diet among patients at high risk of cardiovascular disease (CVD).32 A study is currently taking place that looks at the effects of a mobile health intervention (Healing Circles) with peer support on self-management in CVD.33 Last, the Vet-COACH Study is looking at the impact of a peer health coach intervention on cardiovascular health among veterans with CVD risk factors.34 That being said, there is no report, to our knowledge, of a peer mentoring intervention aiming to improve CVD among kidney transplant recipients.

The development of a peer mentoring intervention requires training mentors. The need to provide mentors training on empathy, communication techniques, and confidentiality as facilitating factors was also highlighted by our participants. Different types of peer mentor training are reported in the literature. Most of the training curriculum for peer mentors or coaches involve a session on communication techniques (active listening, nonjudgmental communication, and motivational interviewing), medication and the importance of adherence, self-management skills, lifestyle changes, emotional support, and navigating through clinical and community resources. 19,35,36 Matching peer mentor and mentee was also mentioned as a facilitating factor for the participants in our study. A qualitative study with veteran women has shown the importance of compatibility between the mentor and the mentee. In that study, participants wanted to share common characteristics with mentors. This could facilitate building trust between the peer mentor and the mentee.<sup>37</sup>

In the past year, a peer mentoring program was implemented in our institution for patients following hand replantation. The objective of this program was to decrease the feeling of isolation felt by patients after a traumatic hand injury and increase adherence to the rehabilitation program. In this program, mentors were patients who had previously undergone hand replantation. All mentors had to go through a training program. All patients hospitalized for hand replantation were approached by the surgeon about this program. If the patient consented, the mentor met the patient during hospitalization and during the follow-up visits. In a pilot study comparing

the functional outcomes of 9 patients who participated in this peer mentoring program versus 43 patients who did not, the authors showed that patients who participated in the peer mentoring program had superior functional outcomes than patients who did not.<sup>38</sup> This is 1 model of peer mentoring that could be explored for new KTRs. However, other peer mentoring interventions could also be developed for the different transplantation stages or as needed by the patient.

Although peer mentoring seems a promising intervention for the participants, our study has limitations. Among these is the small sample of participants, who were mostly Caucasian and highly educated. It is also possible that only KTRs interested in, or who had a positive attitude toward, the peer mentoring program participated in our study. Moreover, many participants had informal experience in helping other patients either on dialysis or after transplantation, which could explain why they were supportive of a peer mentoring program. Despite the small study sample, there was consensus on the importance of developing a peer mentoring program in kidney transplantation.

#### **CONCLUSION**

KTRs who participated in this study expressed a need for the development of a peer mentoring program to help other KTRs face the challenges associated with kidney transplantation, with some of them willing to be mentors. Peer mentoring could also play a role in cardiovascular disease prevention. Further research is needed to document the impact of the presence of KTRs mentors at the outpatient clinic and in the hospital ward. It would also be important to determine the best conditions to implement a peer mentoring program in kidney transplantation and address the different barriers identified by patients.

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