Qualitative Arm- Focus Group/Interview Guide

Introduction:

Welcome everyone! I want to take this opportunity to thank you all for participating in our focus group today. My name is (_____________) and I am the facilitator and beside me, we have our co-facilitator (_________________) who will also be helping me today in our group discussion.

The goal of our focus group today is to understand what you think about kidney disease, kidney failure, kidney transplant, and organ donation. We would also like to know about any barriers or challenges you may have experienced when trying to access information or care related to your kidney health, or your health in general, and any suggestions you may have to overcome these barriers and challenges. We are interested in all of your experiences, opinions, beliefs, thoughts, and feelings about these issues and there are no right or wrong answers. So, please feel free to speak openly and honestly. It is my job to guide our discussion today. I will make sure everyone who wants to speak has a chance to do so. I will also make sure that we stay on track in terms of our topic and our timing. But, hopefully, you will do most of the talking and (_________) and I will mostly listen.

Our focus group will run for approximately 1½ - 2 hours. If you do need to step out during the group discussion, please feel free to do so.

Ground Rules:

I would like to set some ground rules to ensure that everyone in the group feels comfortable and safe during our discussion. Is that ok with everyone?

[If yes, have everyone proceed to create ground rules]

Sample Group Rules:

- One person speaks at a time (i.e., Taking turns before speaking)
- Respecting each other's opinions (i.e., members will show respect in a non-judgmental way)
- Privacy/confidentiality (i.e., what is said in the group, stays in the group. Each member will respect each other's personal information and will not reveal that information outside of the group)

[Clarify ground rules or uncertainty with participants when needed]

- As you already know, we will be recording today's discussion. Our conversation will be audio recorded and then transcribed, so that we do not lose any of the information that is discussed and it will be easier for the research team to analyze.

Please be assured that your personal information will be kept private within our research team. Is everyone comfortable with this?

[If yes, proceed forward and if no, answer additional questions participants might have]

Turn on Audio Recorder.

Participant Introduction:

1.) Let's start by going around the room to introduce ourselves. Will each person please tell us:

  a. Your preferred name
  b. Tell us briefly your connection, if any, to kidney disease, organ donation, and kidney transplant, and/or, why you chose to participate in today's discussion

Focus Group Questions

Ethnocultural Identity

1. Which ethnocultural group(s) do you identify with and what does this mean to you?
    a. What does this look like in your everyday life? (e.g. language, food, traditions, approaches to health and healing)

2. In what ways do you think your ethnocultural identity as [participant answer] influences your experience with the health/kidney care system?
    a. Do you feel that you experience the healthcare system differently than others? If so, why do you think that is?
    b. How have these experiences shaped how you interact with the health care system?

3. What types of healing & treatment practices are important to you?
    a. Do you use any healing practices that are different than the treatments typically provided by the Canadian healthcare system?
    b. Are there any factors that you consider that make you lean on one approach over the other?
        i. Probe around access, finances, quality of experience, results.

4. Are you aware of any thoughts, feelings, or concerns in your community around kidney disease, kidney transplant, and organ donation?

Next questions will need to be modified for community members vs. patients on dialysis, recipients, donors, family members/caregivers. For example, for participants with lived experience of CKD, participants can answer questions based on their actual vs. a hypothetical experience.

General Knowledge & Awareness

1. What do you know about the kidneys and their function?
    a. How would a person know if their kidneys were not working properly?
    b. What do you think causes kidney disease?
    c. What is kidney failure?
    d. How serious are kidney disease and kidney failure?

2. If someone has kidney failure what are their treatment options?
    a. Do you think that one option is better than another? Why or why not?

3. What do you know about kidney transplant as a treatment option?
    a. If someone needed a kidney transplant, where could they get a kidney?
    b. What is the difference between a deceased and living donor transplant?
    c. What do you see as the advantages or disadvantages to the different types of kidney transplant?
        i. Probe around risks and benefits of each.

4. What do you know about organ donation?
    a. Probe around living vs. deceased organ donation.

5. How did you come to learn this information? Do you feel that you know enough about these topics?
    a. *If patient or caregiver:* What did you know about these topics before diagnosis? What do you wish you had known about these topics prior to diagnosis?

Family and Support

1. If you had kidney failure and were considering your treatment options, who would you talk to? Who would you rely on for support (emotional, practical)?
    a. What about if you had a different health problem? What about another type of problem, such as financial?

2. If you had kidney failure and required a transplant, would you accept a kidney? Why or why not?
    a. Would you accept a kidney from a living donor? If yes, who would you accept a kidney from?

    b. Would you accept a kidney from a deceased donor? Why or why not?

3. If you or someone in your family/community had kidney disease or kidney failure, what effects could this have on your/their relationships in the family/community?
    a. What about if they needed a transplant?

5. If you or someone in your family/community wanted to be a living kidney donor, what effects could this have on your/their relationships in the family/community?

6. How can relationships with family/friends change in the context of organ donation/kidney transplant?

7. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with family and friends?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with your family and friends?
    c. What would help make discussing these topics easier?

Information Needs

1. Where do you go to find health information or to learn more about your health-related concerns?
    a. Have you encountered any difficulties when seeking information or resources related to your health?
    b. What about your friends or family?

2. *If patient or caregiver:* Have you (or your family and friends) encountered any difficulties when seeking information or resources related to kidney disease, kidney transplant, and organ donation?
    a. What information or support did you receive related to your treatment options?
    b. What types of resources were helpful to you? What resources were not helpful? What else would you need?
    c. Do you think you know enough about these topics? Is there any more or different information that you desire? If so, what kind of information are you looking for?
    d. Are there particular resources or supports regarding kidney disease and its treatment that you would recommend to others?

Religion and Cultural Values

1. How do you think your culture influences how you or your family, friends, community members think about kidney disease and transplant?

2. What about religion and spirituality? How does that shape how you or your family, friends, community members think about these topics?
    a. Is it acceptable to donate your organs while alive? After death?
    b. Is it ok to accept an organ from another?

3. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with community members or religious leaders?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with these individuals?
    c. What would help make discussing these topics easier?

4. If you had kidney failure, what factors do you think might impact your decision regarding your treatment options?
    a. Would you consider both dialysis and transplant? Living donor kidney transplant? Why or why not?

5. What are some of your values and beliefs (if any) that would impact your decision to have a living donor kidney transplant? To donate a kidney either before or after your death?

Immigration & Society

1. How do you think immigrating to Canada impacts the way people receive support related to kidney disease or transplant?

2. What issues do you think immigrants to Canada face if they have major health concerns?
    a. Probe: What about those wishing to pursue LDKT or be living donors?

3. Have you or your family members faced any barriers to accessing health/kidney care in Canada?

4. Are there similarities and differences in the way kidney transplant awareness is delivered here and in other places where you have lived?

Trust

1. Would you say that you trust the Canadian health care system? Do you trust your doctor/healthcare team? Why or why not?
    a. Probe around experiences, attitudes, outcomes, follow through, access to alternatives.

2. Can you remember a situation where you or someone you know did not fully trust the healthcare team looking after them?

3. Have you had any negative experiences in healthcare in Canada where you felt you were being discriminated against (because of your age, sex, gender, race, ethnicity, religion, language skill etc.)?

4. When speaking with your health care provider/team, do you feel respected? Why or why not?

5. How does your health care provider/team integrate your values (e.g. religious/cultural) and beliefs when discussing matters related to major health issues, such as kidney transplant?

6. If you needed treatment for a serious health condition, such as kidney failure, would you want to have it done in Canada or elsewhere (e.g. your country of origin, another country)?

7. Would you feel more comfortable receiving treatment if your health care provider was from the same ethnocultural background as you? Why or why not?

Closing Questions

1. How can we create a better system of care for people with kidney disease from ACB communities?

2. How can we better support ACB community members wishing to be living donors?

3. Is there anything that we have missed today that you think is important for us to know? Do you have anything else at all to add to the discussion?

Conclusion:

On behalf of the research team we would like to take this opportunity to thank you all for participating in our focus group today. You have shared some very interesting and important information. We hope that today’s discussion has been enjoyable for you and if you think of anything else that you would like us to know, please do not hesitate to contact us anytime. Thank you!