

PATIENT INTERVIEW

IMPQ4



Introductions

- 1) How are you feeling today?

Health history

- 2) Can you tell about me what happened to your kidneys?
- 3) What do you think is the cause of your kidney disease?
- 4) What have the specialists told you was the cause of your kidney problem?
- 5) Does anyone else in your family have this same kidney problem?
- 6) Are you taking medications/medicines as well - can you tell me what they are?
- 7) Do you have to do any other particular things to do as part of your treatment (diet, fluid)
- 8) Do you have a local doctor/GP here as well as the kidney specialist ?

Social & Psychosocial context

- 9) Who is your main helper/support person/carer?
- 10) How do they help you?
- 11) Do you talk to your family about this treatment? What do they say?
- 12) What are the main problems for you at the moment ?
- 13) Where do you go for help?

Attitudes/values

- 14) How has your life changed since you started on dialysis/got a Tx?
- 15) How do you feel now about your situation? (anger, sadness, OK, shame, disappointment)
- 16) Do you think anyone is to blame for this illness?
- 17) Is there anything you could do to improve your own situation? How would you do that?
- 18) What's most important to you at the moment?

Treatments

- 19) How long have you been on this treatment?
- 20) Are you happy about the treatment you are on at the moment?
- 21) Why did you choose that one?
- 22) Do you think you will be staying on this treatment?
- 23) Are you involved in decisions about your treatment?
- 24) How do you feel when you go on dialysis/the dialysis machine?
- 25) Does dialysis cause you any sort of problems - can you tell me about them?
- 26) Do you ever miss out your dialysis treatments? What sort of things cause you to miss out dialysis?
- 27) What does missing dialysis do to your health?

Information & Communication

- 28) How do you learn about your kidney illness and the different treatments?
- 29) Do you get enough information to help you understand things well?
- 30) Is there anything you would really like to know more about?

- 31) Do you have any problems understanding what the kidney specialist talks to you about?
What about the nurses?
- 32) Have you said anything to them about that problem?
- 33) Have you ever asked the specialist or nurses questions about your illness or your treatment? What questions were they?
- 34) What sort of things have other patients told you about the treatments?
- 35) (For non-English/ESL) Are you able to get any information in your own language?
- 36) Have you ever had an interpreter to help you?

Transplantation

Group A: Patients on Dialysis

- 1) Have you thought about a Tx?
- 2) Could you talk about why you're interested/not interested in a Tx?
- 3) Have the specialists talked to you about getting a Tx? When was that?
- 4) Has anyone else talked to you about getting a Tx?
- 5) Have you ever asked anyone about getting a Tx?
- 6) Are you on the Tx list at the moment?
- 7) (If 'yes') What are the main things that you need to do if you want to get a Tx?
(If 'no') What are the main things that you need to do if you want to get on the list?
- 8) Do you know anyone who has had a Tx? What do they say?
- 9) Have you heard any good/bad stories about other people who had a Tx? Does that make you think that Tx is good/bad?
- 10) From what you know, do you think people who get a Tx are happier?
- 11) Does your family know about transplantation? What do they say about it?
- 12) Have you heard about family members giving a kidney? What do you think?

Group B: Current Tx patients

- 1) How has Tx changed things for you? Better/not better?
- 2) How did you make your decision about getting another kidney?
- 3) What was the most difficult thing for you as far as having a Tx?
- 4) Does your family know about your transplant? What do they say about it?
- 5) As a person with a Tx, what are the main things that you need to do for your health?
- 6) Did you know anyone else who had a Tx? Did you talk with them about it first?
- 7) Had you heard any good/bad stories about other people who had a Tx?
- 8) Do you have any problems or worries now about this treatment?

Group C: Patients who have had Tx/s and then moved back to dialysis

- 1) Do you mind describing what happened with the Tx?
- 2) Do you think you would say 'yes' again if another kidney came up for you?
- 3) What was the most difficult thing for you as far as having a Tx?
- 4) Did you know anyone else who had a Tx? Did you talk with them about it first?
- 5) Had you heard any good/bad stories about other people who had a Tx?

F. Satisfaction

38 & 39 see Record of Interview sheet.

- 40) When did you last talk with the kidney specialist?
- 41) Do the staff here treat you well?
- 42) Is this a friendly and comfortable place to have your dialysis treatment?
- 43) If you were in charge of this unit/dept is there any particular things you would change?