

Supplementary File: Interview guide

Introductory Remarks:

You are being asked to participate in this research project because I would like to hear about your experiences as a parent caring for a child with ESRD.

The interview should take approximately 30–50 minutes. With your permission it will be digitally recorded to ensure that all key points are accurately documented. Any identifying information, such as names of individuals that you use in the course of our discussion, will be changed to aliases or initials in the interview transcripts. If you wish to end the interview before I have asked all of the questions or you wish to withdraw from the study, you are free to do so at any time.

It is important to note that there are no right or wrong answers to the questions and that no one will know what your specific answers were. I am aware that some issues or questions may arouse powerful emotions; it is therefore understandable if you wish to pause and return to these key issues at a later time.

Note to interviewer: Try and keep the interview as open-ended as possible following the initial inquiry. Make use of the supplemental questions and probes, if key issues do not arise spontaneously. The order in which these questions and probes are asked can be changed according to how the participant answers the questions and the child's current medical condition and stage of renal disease. The order and pace can also be changed according to the degree of emotional exposure. When parents discuss novel concepts, such

as stress or other emotional expressions, invite further inquiry by asking them to elaborate on their statements.

Guiding open-ended questions:

I would like to hear about your experience as a parent of a child coping with end stage renal disease. Feel free to relate to any aspect of your experience. These can be past or present experiences and can also include your feelings and thoughts about the future.

1. Can you describe your thoughts and feelings when your child was first diagnosed with ESRD?

Probes:

- Can you please elaborate or give an example of one of the key difficulties you faced following diagnosis?
- Can you elaborate on the changes that occurred in your life following diagnosis?

2. What is it like to care for a child with ESRD ?

Probes:

- Could you provide me with an example of some of the key difficulties/challenges, emotional or otherwise, you face as a parent caring for a child with ESRD?
- Can you share the effects of coping with ESRD on your marital, professional, and family life?

3. What it is like to care for a child with ESRD during dialysis?

Probes:

- Can you please elaborate or give an example of some of the key difficulties you faced during dialysis treatments?
- What were your thoughts on organ transplant during dialysis treatment?
- When you look ahead, what do you think/hope will be ?
- Can you elaborate on the major changes that occurred in your life during dialysis treatment?

4. Can you share with me some of your thoughts and feelings about organ transplants?

Probes:

- Pre-transplantation
- During renal transplantation
- Post-transplantation
- Organ donation

5. What is it like to care for a child with ESRD after a kidney transplant?

Probes:

- Can you please elaborate or give an example of some of the key difficulties you faced after the transplant?
- How would you describe the changes that occurred during the transition from dialysis to post-transplantation?
- Can you elaborate on the major changes that occurred in your life after the transplant?

- When you look ahead, what do you think/hope will be?

6. What would you tell other parents about what it is like to care for a child with ESRD?

Closing remarks:

I would like to thank you for participating in this research project. If you have any questions regarding our meeting, please ask them now. Sometimes, especially after talking about sensitive and emotionally-charged topics, questions and thoughts can emerge at a later point in time. Feel free to contact me for any reason at all in order to schedule another meeting to talk about the interview.