

Appendix 3. Semi-structured interview guide and observation forms

Appendix 3a. Interview guide: Patients with Chronic Kidney Disease

Duration Interview: 45-60 min

- A. Introduction, explanation, consent
- B. Demographic data:
- Identification number, sex, age, education, profession (e.g., type of work, daily routine)
 - Personal and cultural background (e.g., family situation – and size, composition, religion)
 - External health-related conditions (e.g., distance to a health care facility), disease stage
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- C. Topic lists of belief, perception of disease
1. How do you feel when you were told that you had CKD?
(Probe: What do you think has caused this problem? Did you have any worries or concerns, the most fear?)
 2. How do you feel of having CKD?
(Probe: What do you know about CKD? What are the changes in your life/impact? How? How do you cope with these impacts)
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- D. Topic lists of belief, perception of self-management
- Attitude toward self-management
3. Do you know self-management?
 4. How do you feel about self-management? And why?
(Probe: Do you have experience with it? What can you do? How do you think of the advantages of self-management? How do you feel about disadvantages of self-management?)
- Subjective norms in self-management interventions in CKD and normative beliefs
5. How do you think others' feelings of self-management?
(Probe: government nurses, doctors, your caregivers? Other stakeholders for approving or disapproving?)
- Perceived control in self-management interventions in CKD, barriers and facilitators
6. Do you feel that you would be able to manage the disease by yourself?
(Probe: Do you have confidence in self-management in CKD? Facilitators? Barriers?)
 7. How do you perceive your role in self-management?
(Probe: do you think you, as a patient, should be actively involved in managing your disease? Is it your role/ duty as a patient?)
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- E. Topic lists of needs toward CKD self-management
- Current care
8. How do you manage CKD?
(Probe: What kind of support do you get of CKD care? Who, what?)

Feelings, challenges, barriers

9. How do you feel of your CKD care or the current care provided to you?
(Probe: What are good aspects of CKD care? What are the problems, challenges of CKD care? What are the problems, challenges of managing the CKD by yourself?)

Needs of CKD self-management

10. Is there anything else that should be done to support you to manage CKD?
(Probe: What for CKD management should be done in the future, when, and from whom?
What support should be done to support your self-management of CKD?)

Appendix 3b. Interview guide: Health care professional

Duration Interview: 45-60 min

- A. Introduction, explanation, consent
- B. Demographic data (Baseline data):
- Name, sex, age, profession, education (the type of work, years of work experience, type of healthcare facility)
 - Personal and cultural background (family situation – and size, composition, religion)
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- C. Topic lists of belief, perception of disease
1. How do you feel about CKD?
(Probe: What is the impact of CKD? and how?)
 2. How do you tell patients that they have CKD?
(Probe: What will you tell patients that they have CKD? What worries and concerns of their future?)

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- D. Topic lists of belief, perception of self-management

Attitude toward self-management interventions in CKD and behavioural beliefs

3. Do you know self-management?
4. How do you feel of self-management in patients with CKD? And why?
(Probe: Do you have any experience with it? How do you think of the advantages of self-management? How do you feel about disadvantages of self-management)

Subjective norms in self-management interventions in CKD and normative beliefs

5. How do you think others' feelings of self-management?
(Probe: government, nurses, patients, patients' caregivers? Other stakeholders for approving or disapproving?)

Perceived control in self-management interventions in CKD, barriers and facilitators

6. How do you think the possibility of self-management in patients with CKD?
(Probe: Do you have confidence in self-management in CKD? Facilitators? barriers)
7. How do you perceive your role in patients' self-management? What is your responsibility?
(Probe: Are you willing to be more involved in the patients' self-management? Can you explain in which way you want to be involved?)

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- E. Topic lists of needs toward CKD self-management

Current care

8. Can you tell me about your ongoing care for the patients with CKD?

(Probe: What are your roles in clinical care? What types of care will you give to patients? If you follow some kinds of protocols for their care? Are there some protocol contains something related to self-management?)

Challenges and barriers

9. Do you have any barriers in the health care of CKD management?
(Probe: Do you have some challenges in patient care? Do you have some barriers to promoting patients' self-management?)

Needs of CKD self-management

10. Is there anything else that should be done to support you in the clinical care of CKD?
(Probe: Do you have some suggestions for the management? What sorts of programs or support should be done to support self-management for patients?)

Appendix 3c. Observation list

Study Setting _____Location of consultation/Clinic _____Details

outpatient clinic/ daily clinical care

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(please specify)Healthcare worker description

Male / female Age: _____ Education: _____

Profession: _____

Total years work experience: _____

Years of work experience in community: _____

Patient description

Male / female Age: _____ Stage: _____

Comorbidity: _____

Activity _____

Observer _____Start

_____ : _____ AM/PM

End

_____ : _____ AM/PM

Please circle the option that you observe. If you observe option 2, this would look like:

option 1 (option 2) / option 3

If more than one option is observed, please circle every applicable option

1) Belief, perception toward disease

a) Health care professionals: 1. feelings of CKD 2. concerns of CKD**b) Patients:** 1. Feelings of CKD 2. Changes in life 3. Impacts of CKD 4. Coping with

2) Belief, perception toward self-management

a) Health care professionals: 1. Attitude 2. Subjective norms 3. Perceived control 4. Professional role

b) Patients: 1. Attitude 2. Subjective norms 3. Perceived control 4. Professional role

3) Describe: interaction between the health care professional and the patient

a) Description of the communication (e.g., adherence, future concerns, sensitive and personal issues)

b) Are there times when it has been hard for patients to follow what has been told by health care professionals? Why?

c) Whether patients can ask questions openly with your doctor?

4) Needs of CKD self-management

a) Health care professionals: 1. Current care 2. Challenges and barriers 3. Needs

b) Patients: 1. Ongoing care 2. Challenges, barriers, feelings 3. Needs

c) Caregivers: 1. Current involvement 2. Challenges and barriers 3. Needs

Additional remarks and observations

