

# The experience of kidney patients: A qualitative research

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# Background

- Ideal approach in nephrology care is to timely referral, timely education and timely start to replacement therapies,
- Many studies have shown that patients with CKD are generally lately referred to the nephrology team and associated with increased morbidity and mortality.

# Aim

The purpose of this study was to determine the physical and psychosocial experiences of dialysis patients before and after the initiation of treatment and disease management.

# Method

- Two focus groups were conducted at two hospitals
  - in order to learn the patients' knowledge and experience about disease management in a qualitatively designed semi-structured study.
- 14 patients participated to the study.
- Informed consent of patients was obtained.

# Method

- 1 focus group was interviewed in the patient's education room, and 1 focus group was interviewed in the hospital's meeting room.
- During the intervention, 2 rapporteurs kept records, voice recording was received at the same time.
- For each group, discussion was planned to last 120 minutes.
- During the patient focus group interviews, there were no clinicians.

# Method

- Voice recordings of participants and discussion were fully conveyed.
- Precautions were taken to ensure patient information security, the names of the participants and institutions were kept secret.
- Transcripts and analysis were carried out by two academicians together with the researcher.
- In the evaluation of the data, content analysis method was used.

# Method

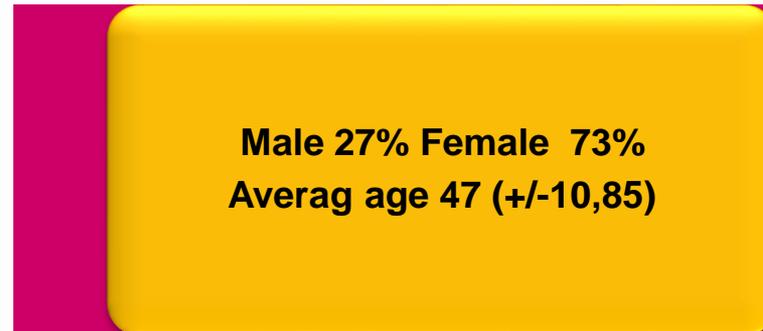
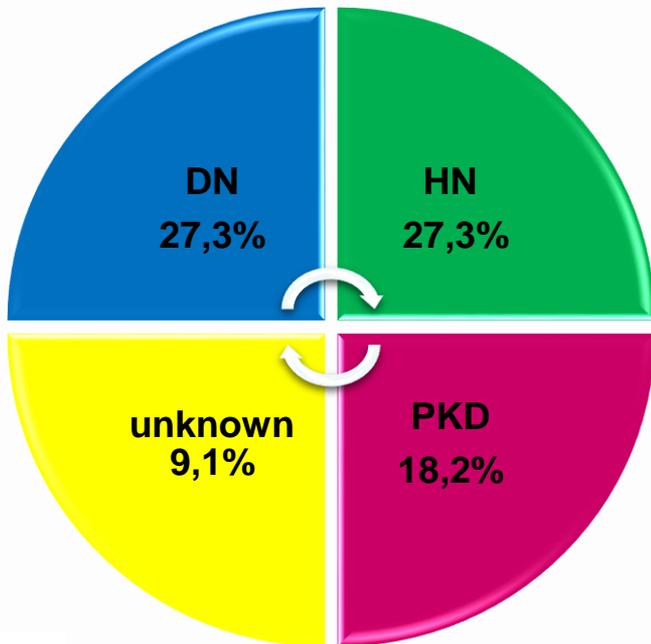
## Focus group questions:

1. Did you know about kidney diseases and treatment options?
2. Have you been informed about your illness before start the treatment?
3. Who and how was decided to start treatment?
4. Did you choose your treatment, have you received any support while choosing your treatment?
5. What was the reason for choosing this treatment?

# Method

6. How does the opinion of your doctor and your nurse influence your treatment choice?
7. What are the ease and difficulties you face when applying your treatment? How did you adapt your treatment to your daily life?
8. What is the most important issue for you in treatment decision?
9. How would you like to be supported if you stay in the process of making a decision about your treatment today?

# Results



# Results

5 major themes were identified.

1. The first theme was “Predialysis education or information”, revealed how patients received education or information before dialysis initiation

2. Second theme was “initiation process of renal replacement therapy” included the process of starting dialysis in planned or emerged manner

3. Third theme identified “treatment decision support”,

4. Fourth theme was “expectation from treatment”

5. “treatment burden”

# Results

## Themes

### Disease related knowledge

- «I had no knowledge, they took me to a room, they did a small operation at five o'clock in the evening, asked me during the operation if i am married and do i have any children»  
«I did not know what dialysis was, I thought I would get better when I took the medicine. When I learned my illness, it was too late»

### Dialysis initiation

- «My mother was on dialysis, i have learned from her and she supported me»  
«I talked to my parents ask their thought about dialysis, they told me this is my decision, they did not intervene, I had to make my own decisions without any support»  
«The doctor recommended peritoneal dialysis since I was young»

### Treatment decision support

- «I learned through experience, I did not receive guidance on support»  
«Dialysis patients need to go to a single hospital, it must be a team, it is very important to reach the hospital, doctor and nurse when we need it»

# Results

## Themes

### expected from treatment

- «Treatment should not cause physically or psychologically harm»  
I must be able to continue my social life,
- «I should be able to keep my daily life more normal, should not be restricted to drinking and eating »
- «I should be able to ask questions
- « Education, home visit, support at home is important»

### Therapy burden

- «I did not accept hemodialysis because I was working. I connected to the peritoneal dialysis »
- «I was anxious, I was shaking hands at first practice, I did not know my own future»
- «Education is very important, I am relieved when I receive education»
- «I feel guilty when I have problems».
- «it is not easy to continue the dialysis sessions, I have to leave my work»
- «my family is accompanied by my dialysis sessions with me, I think I am a burden to them»
- «I learned very hard how to deal with dialysis treatment»

Analysis showed that «patients are not sufficiently trained or even informed on kidney disease and treatment options'»

«majority of patients start dialysis in emergency conditions»

«they do not get any support during their decision making process about starting dialysis treatment»

«they have difficulties in adapting their treatment to their everyday routine and managing their treatment process»

# Conclusion

Findings identify the importance and need of a systematic predialysis education and support/counseling for patients to make informed decisions.