

Illness experience in nephrotic syndrome

Anneli Jönsson, RN, PhD (C)

Department of clinical sciences
Lund University
Sweden



What is nephrotic syndrome?

- A collection of symptoms:
 - severe proteinuria (>3.5 g in 24 h)
 - low plasma proteins
 - severe and generalized edema
 - hyperlipidaemia
- Incidences in adults are approximately 3/100 000
- NS is rare, but a serious clinical condition:
 - ESKD
 - infections
 - cardiovascular events



Nephrotic syndrome

- Primary or secondary cause
- Most common causes in adults:
 - Membranous nephropathy
- Most common causes in children:
 - Minimal change nephropathy
- It is chronic
- Remissions -relaps

(Cattran et al., 2017, NDT 32:1).



Why this study?

- Little is known about health and wellbeing among patients with nephrotic syndrome.
- Aim:
 - To explore patients' experience of suffering from nephrotic syndrome

Participants

Newly diagnosed as well as relapsed adult patients
(n=10)

Minimal Change Nephropathy
(2 female and 1 male)

Membranous Nephropathy
(2 female and 5 male)

Median age: 66.5 years (range 21-90 years)



Method



- Between 2016 - 2019
- Open-ended interviews
- Data analysis:
 - Phenomenology hermeneutical method (Lindset & Norberg, 2004)
 - Naïve reading
 - Structural analysis
 - Comprehensive understanding



The naïve reading

Patients with NS are in a **state of ambiguity**, the disease and its consequences do not make sense to them and they have no idea what to expect or do.

NS is a condition in which **the meaning cannot be defined by the patients**. They cannot make sense of something that makes no sense which leads to a complete **lack of coherence**.

Structural analysis

Themes	Feeling ill and well at the same time	Being passively adherent	Being in uncertainty	Trying to comprehend and cope
Sub-themes	Experiencing physical changes	Avoiding asking questions	Doubting the future	Seeking information
	Not noticing or understanding symptoms	Trusting healthcare professionals	Wondering about causes and prognosis	Acknowledging family support
	Being affected by the disease but managing everyday life	Feeling powerless	Questioning one's own role	Willing to make lifestyle changes

“

From what I have understood, this is a disease that develops slowly. I have read about it, but haven't noticed any signs myself.

”

Male, 71 years

Feeling ill and well at the same time

- Not noticing or understanding symptoms

“

The doctor says I should take them, so I do. I must obey. I question nothing, neither the injection nor the tablet. They must be good, otherwise I would not have received them

”

10

Female, 65 years

Being passively adherent

- Trusting healthcare professionals

“

I don't know what to do. They haven't really explained that to me. If it gets worse I really don't know what will happen

”

11

Male, 21 years

Being in uncertainty

- Doubting the future

“

What kind of information is there about the diagnosis? How do I find the right information?"

”

12

Female, 36 years

Trying to comprehend and cope

- Seeking information

Conclusion

- An in-depth understanding of the illness experience among patients with NS
- Person-centered care for patients with NS
- Clinical guidelines:
 - Treatment
 - Follow-up
 - Health promotion
 - Renal nursing
- And of course; more research of patients experience!

Co-writers

Anna Forsberg

Professor

Care in high technological
environments

Lund University

Thomas Hellmark

Associate professor

Nephrology

Lund University



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*Thanks for your
Attention!*

