The Human Perspective - Essential when we Developed Self-Dialysis

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Presentation

Christian Farman
• Registered Nurse
• Technician NDT
• President of the Kidney Association of Jönköping/Kronoberg Counties
• Patient/customer/caretaker/client since 1997
• Kidney transplant 2,5 times
• Peritoneal dialysis 1 year in 1999
• Self-hemodialysis 1 year in 2005
Supernurse

- Britt-Mari Banck Reg. Nurse and Deputy Chief Nurse at the Dialysis Unit in Jönköping
- Dialysis nursing experience for more than 20 years
- Developed an unique learning model together

What Does it Mean to Receive Dialysis Treatment in Chronic Renal Failure?

- Life supporting treatment
- Dialysis treatment at least 3 days a week
- It takes 4-5 hours a day
- Food restrictions
- Fluid restrictions
- Extensive pharmaceutical treatment
- Limitation in social life
- Separation from family and work
My Situation Back in 2005

- Relapse in renal failure
- In need of dialysis treatment
- Anemia/Uremia

**Symptoms**

- **Nausea**
- **Fatigue**
- **Thirst**
- **Itching**
- **Edema**

I Put Demands on the Health Care Provider/System

- Learn to manage my own dialysis treatment
- Optimal individual dialysis treatment
- That the health care provider was listening to my needs
- Daily dialysis or at least 5-6 days a week
- To be fully involved and have influence over my dialysis regime and treatment
We Started With the Hardware and Software...

...and Then Proceeded
Another Step Towards Independence...

...and Then: Did it by Myself!!
What I Learned When I Made Demands on the Health Care System

- Ability to influence my life situation
- Anything is possible with right guidance
- Meaning and Sense of Coherence
- Involvement and better treatment outcomes
- Quality of life
- Health and wellbeing
- Gainful employment despite extensive treatment

Everybody can do it!!
The Self-Hemodialysis Staircase

The staircase is not static. Changes can go both upwards and downwards depending on the patient's condition and motivation. Training and information is provided along the entire staircase.

Visitor at the Self-Dialysis unit, receiving information about self-dialysis.

"Dresses" and primes the machine at start-up, with some supervision. Write protocol.

Manages the machine at start-up and conclusion with supervision. Gets help with inserting needles or handling the CDK. Cleans up. Manages alarms.

Manages the machine independently. Inserts and withdraws needles/ manages CDK with some assistance. Cleans up.

Manages everything without supervision.

Home-HD

Out-patient clinic
Emergency care
Peritoneal dialysis
Assisted HD

The Work Load Staircase – SHD

How much staff is needed for different work loads?

3 points – 1 nurse/2 patients?
2 points – 1 nurse/patients in training (Yellow steps 1-2)
1-2 points – 1 nurse can attend to several patients (Yellow step 3)
1 point – 1 nurse can attend to several patients (Green steps 1-2)
0 points – 2 nurses/11 patients (Green step 3)

1. Training
Dress the machine. Primes, sets the table
1 point – 1 nurse can attend to several patients (Green steps 1-2)
0 points – 2 nurses/11 patients (Green step 3)

2. Training
1 + start conclude the dialysis with assistance/ supervision
2 points

3. Training
1 + 2 + Only supervision. Learn to insert needles/use CDK
2 – 3 points

4. Continuous training
Drawing UF
Medications
Kt/V
Blood volume-assessment
Blood pressure

4 points

Visit for 2 weeks
Assistance with the HD. Writes protocol, takes blood pressure.

1 point

1-2 points

1 point
Margaret Newman’s Theory

- Health also in the presence of disease.
- Higher levels of consciousness (theoretical and practical knowledge)
- Nurse = Coach; source of knowledge
- Gives necessary knowledge/creates possibilities for reaching the next level of consciousness
- Form new life-patterns
- An active patient who takes responsibility for her/his choices
Responsibility?

What do we Measure?

- ESAS (Edmonton Symptom Assessment Scale)
- Quality Indicators: Blood count, Kt/V, S-Phosphate, Corrected S-Calcium, PTH, Accesses
- Decreased use of medication, e.g. EPO, Blood pressure agents
- In-patient admissions
Success Factors

**Patient participation!**

- Build trust
- Structure
- Be attentive – listen to others
- A sense of security and comfort
- Humor

"Should we call this unofficial labor....?"

"Do you know what’s best about this job? – You can be lazy without it being noticed!"
What Do We Gain Through Patient Involvement?

- Better dialysis quality
- Healthier patients
- Patient adherence
- Less medication
- Quality of life
- Less infections
- Less admissions
- Win-win situation
- Everyone is a winner; the patient, relatives, profession, healthcare system and society

What Can the Health Care System Learn?

- Meet the patient based on his/her knowledge and conditions
- See the person beyond the patient
- Listen to the patient, I mean LISTEN to the patient
- Dare to try something new; think outside the box.
- Don’t focus on problems
- Begin to discuss hierarchies in health care
- Work with the culture
- It’s not about the age issue
"Lets dance" ......together!!

Thank you for your attention!

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