To get a grip on the bladder is work
Specialized nursing guarantees effective self-management after cystectomy and neobladder

Background
Bladder Cancer is the fourth leading cancer with an incidence of 6.5% in men and 2.1% in women. Major risk factor is smoking. 30% of bladder cancer are muscle invasive cancer. The gold standard to treat muscle invasive bladder cancer is cystectomy and neobladder construction. This surgical intervention has considerable impact on physical and emotional integrity of the patients concerned. After surgery, patients have to follow a complex therapy regime.

Role of the specialized nurse and patient rehabilitation
Success of rehabilitation depends strongly on patient’s self-management skills. Therefore, a specific education program was developed and implemented at a Swiss university hospital. The aim of this program is to instruct, educate and support patients by a specialized nurse. She supervises the patients’ self-management skills usually during three to six months, sometimes even for an unlimited period of time. She contacts patients at least four times: Preoperative in outpatient clinic, before surgery on the ward, after surgery before and after catheter removal, and for the telephone call three days following hospital discharge.

Topics of the patient education program
- How does the “new” bladder work?
- Emptying the “new” bladder
- Continence: Pelvic floor & sphincter exercises, reaching adequate bladder capacity
- Metabolic changes
- Hygiene
- Sexuality

Aims
a) To evaluate the patient education program and to assess the added value from the patients’ perspectives.
b) To demonstrate how patients cope with the impact of disease and requirement of therapy after surgery within the first three months at home following hospital discharge.

Method
Longitudinal research design. Ten patients concerned were interviewed three times. It was not possible to hold the second interview with 2 patients because they felt too ill.

Sample & Setting
2 women & 8 men (age 48-73) were interviewed between August 2009 – January 2010.

Results
- Patients benefit considerably from the education program, and rehabilitation is enhanced.
- Interventions have a beneficial effect on patient’s self-management at home and guarantee safe transfer from inpatient to domestic area.
- All interviewed persons could realize self-management of their therapy at home.
- The main challenge for self-management was to get a grip on the bladder.

Conclusions
- Educational interventions by the specialized nurse enhance success of rehabilitation.
- Most suitable patient education interventions start before surgery and continue after discharge from hospital.
- Patients need very high effort to get the new bladder under control and to go back to daily life during the first three months following operation.
- Nurses have to be aware about this process when educating patients and their partners.

Key Categories
Day before discharge
- To get a grip on the bladder
- To prevent metabolic complications
- To deal with fatigue

2 weeks post discharge
- Coping with changes in daily life
- Feeling safe in managing all challenges

3 months post discharge
- Learning to live with cancer
- Living with sexual dysfunction

Results of the patient education program
- Working according a schedule
  - Learning technique of urinating
  - Midcution by the hour
  - Pelvic floor exercises
  - Expanding the bladder
  - Being incontinent repeatedly
  - Value of education
  - Coping at home

Education in 3 Phases
- Tape recorded, transcribed verbatim content analysis approach (Mayring, 2003)