Body composition and Quality of life in patients with IBD, ileostomy and Short Bowel Syndrome

ABSTRACT
Patients with IBD are at risk for intestinal disability (e.g. having a stoma, malnutrition). The general aim of the thesis was to investigate physiological, psychological and social consequences of having IBD and an ileostomy or short bowel syndrome (SBS).

Patients and Methods: Six SBS patients were interviewed to investigate practical aspects on daily life. In 21 ileostomates, and 19 patients with SBS, bioelectric impedance spectroscopy (BIS) was compared with other methods for determination of water compartments and fat free mass (FFM). Differences were analysed using the Bland-Altman method. Concerns, health related quality of life (HRQOL), quality of life (QOL) and coping were assessed in 21 patients with an ileostomy and 28 patients with SBS. HRQOL were compared with a matched group from the general population.

Results: The differences between methods (BIS, Dual-energy absorptiometry (DXA), Dilution and derived estimates) to assess total body water (TBW) and FFM were pronounced. The mean difference of extracellular water (ECW) between dilution and BIS was less in female ileostomates than male, (p<0.01). Hydration of FFM assessed by BIS gave a mean of 0.77 for ileostomates and 0.75 for SBS patients. Most SBS patients were maintained in a stable clinical condition within normal limits of body weight and BMI.

The most serious limitation of every day life for SBS patients was the planning involved to get most out of life. Dominating concerns for the ileostomates were intimacy, access to quality medical care and energy level and for the SBS patients being a burden, further surgery and energy level. Vitality was significantly reduced in ileostomates. In SBS patients all dimensions in HRQOL were significantly reduced except physical function. More than 1/3 of SBS patients rated health worse or much worse than one year ago.

Most definitions on "good quality of life" were found in the social dimension. Most "obstacles to good quality of life" were found in the psychological dimension for the ileostomates and in the physical dimension for the SBS patients. Perceived QOL was rated 70/100 for ileostomates and 64/100 for the SBS patients. Confrontation was the dominating coping style.

Conclusion: The differences between methods to assess body water compartments and FFM were pronounced. Methods could not be used interchangeably. BIS should be further evaluated with repeated, longitudinal measurements.

The high concern for being a burden needs further investigation and how it can be reduced. Concern for intimacy as the concern for loss of sexual drive and sexual performance needs to be further explored. Fatigue needs to be defined. It is also necessary to study how concern changes over time. Integrating items of concern into counselling may result in greater coping ability and improved QOL.

Key words: inflammatory bowel disease, Crohn’s disease, ulcerative colitis, short bowel syndrome, quality of life, health related quality of life, coping, concern, body composition, bioelectric impedance spectroscopy, Dual-energy absorptiometry, total body water