

## Development of a self-care questionnaire for clinical assessment among patients with inflammatory bowel disease

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**Background:** Patients with IBD live with symptoms that are both physical and psychological burdening. Patients need self-care to manage daily life. There is a lack of measures to assess self-care in patients with IBD with the intention to support and strengthen individual efforts to improve their self-care. To offer appropriate care for patients with IBD, individualized self-care advice may aim to maintain health.

**Objectives:** The aim was to develop and evaluate the IBD Self-Care questionnaire for assessment of self-care among patients with IBD.

**Methods:** This is a validation study applying both qualitative and quantitative methods based on recommendations for questionnaire development. An interview study on self-care in patients with IBD (n=20) was performed and opinions about items of self-care was obtained from an expert panel (n=6) and patients (n=100). Data was collected between November 2014 to April 2016 in three phases: (1) item generation based on an interview study on self-care in patients with IBD (n=20), (2) early evaluation including Content validity Index (CVI) was measured by an expert panel and patients were ranking the items to consider selection of items, also cognitive interviewing was used in a pre-test to determine the usability of the questionnaire and (3) final evaluation with a pilot study (n=30) and test-retest (n=50). Test-retest stability was established after three weeks. Validity was considered through two follow-up questions. Quantitative and qualitative analyses resulted in a reduction of the items from 51 items into 9 questions and 16 quotations.

**Results:** A total of 180 patients with IBD participated in this study, of who 86 with Crohn's disease and 94 with ulcerative colitis. The IBD Self-Care questionnaire consists of 9 questions and 16 quotations and the first version is developed in the Swedish language. Evidence of initial validity could be demonstrated with the involvement of an expert panel and patients with IBD. Reliability in test-retest statistics of responses on each item showed between measure 1 and 2, 78-98% conformity, except for one item (38%).

**Conclusion:** This study contributes to an individual disease-specific assessment of self-care through the development of a new IBD Self-Care questionnaire for assessment of self-care among patients with IBD in Sweden. Further studies, prospectively are needed to test the IBD Self-Care questionnaire in a sample of English speaking participants.

### Biography:

Registered Nurse, MScN Ulrica LovénWickman is a PhD student at Linköping University in Sweden. She is working in the field of Primary Health Care in southeast Sweden. Her research is about self-care among patients with inflammatory bowel disease (IBD). Her doctoral dissertation is focused on development and validation of a self-care questionnaire for patients with IBD for clinical use.