

A gender perspective on irritable bowel syndrome Symptoms, experiences and the development of a person-centred support intervention

Akademisk avhandling

som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, Göteborg, torsdagen den 8 december 2016 klockan 13.00

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Avhandlingen baseras på följande delarbeten

- I. Björkman, I., Jakobsson Ung, E., Ringström, G., Törnblom, H. & Simrén, M. 2015. More similarities than differences between men and women with irritable bowel syndrome. *Neurogastroenterology & Motility* 27(6), 796-804.
- II. Björkman, I., Dellenborg, L., Ringström, G., Simrén, M. & Jakobsson Ung, E. 2014. The gendered impact of Irritable Bowel Syndrome: a qualitative study of patients' experiences. *Journal of Advanced Nursing* 70(6), 1334-1343.
- III. Björkman, I., Simrén, M., Ringström, G. & Jakobsson Ung, E. 2016. Patients' experiences of health care encounters in severe irritable bowel syndrome: an analysis based on narrative and feminist theory. *Journal of Clinical Nursing* 25(19-20), 2967-2978.
- IV. Björkman, I., Simrén, M., Ringström, G., Myrgren, J. & Jakobsson Ung, E. The role of the nurse in the management of irritable bowel syndrome: development and pilot study of a person-centred support intervention. *In manuscript*.

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Abstract

Irritable bowel syndrome (IBS) is a common functional gastrointestinal disorder which affects approximately ten percent of the world's population and which is more prevalent among women than men. The hallmark symptoms of IBS are abdominal pain and disturbed bowel habits and a number of differences, for example in symptom profiles, between men and women with IBS have been reported. Only a smaller number of studies have explored the patients' perspective on everyday life and health care encounters in IBS, and never from a gender perspective.

The present thesis aimed to explore symptoms, experiences from daily life and health care encounters in IBS from a gender perspective, and to develop and in a pilot study evaluate a nurse-led intervention for IBS.

A multimethod design was applied where questionnaires on self-reported health were combined with interviews with patients.

Among 557 patients diagnosed with IBS it was found that there were more similarities than differences when men and women were compared. However, there was a pattern of difference disfavoring the women, especially regarding health related quality of life. An interview study including 19 patients revealed that the experience of living with IBS was gendered, meaning that social norms on masculinity and femininity affected the experience of symptoms. A subsequent qualitative study including 10 patients with severe IBS showed that their experiences of health care encounters were mostly negative and that they struggled to protect themselves from stigmatizing labeling. The findings from these studies were used in the systematic development of an intervention for person-centred support in IBS. The intervention, which was tested in a pilot study including 17 patients, was found to be feasible, appreciated by the participants, and efficient in reducing IBS symptom severity, whilst there were no significant changes for general self-efficacy or gastrointestinal-specific anxiety.

This thesis contributes to the existing knowledge on IBS through adding a sociocultural perspective on gender/sex and by introducing person-centred care as a viable part of the clinical management of the disorder.

Keywords: irritable bowel syndrome, functional disorder, gender, sex, person-centred care, nurse, intervention, self-efficacy, symptoms, self-management