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Living with inflammatory bowel disease – Health-related quality of life, worries, and stress

AKADEMISK AVHANDLING

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ABSTRACT

Background: Patients with inflammatory bowel disease have a number of worries and concerns related to the disease, and in comparison with a general population their health-related quality of life is impaired. These patients need disease-related information and education. However, it remains unclear how this information should be provided. Disease activity is one of the most important factors for reduced health-related quality of life. Therefore it is also important to assess more information about trigger factors for relapses in inflammatory bowel disease.

Aim: The general aim of this thesis was to gain scientific evidence about worries and concerns, health-related quality of life, and trigger factors for relapses, and to develop and evaluate an education programme.

Method: In all four studies the patients included were diagnosed with inflammatory bowel disease, and in remission. In **Study I,** 93 patients were included and randomized to an intervention group or a control group. The intervention group attended a group-based education programme. Health-related quality of life was measured at baseline and after six months, by using four questionnaires. The intervention group also completed the questionnaires after one month. In **Study II,** 197 patients were included and divided into a Crohn's disease group and an ulcerative colitis group. Each group was also divided into separate groups according to whether the patients had short disease duration or long disease duration. Health-related quality of life was measured using four questionnaires. In **Study III,** 195 patients were included. They filled in one questionnaire: the RFIPC, and two other questionnaires. Confirmatory factor analysis was performed to validate the factor structure in the Swedish version of the RFIPC and to examine fit of different hypothesized models of factor structure. In **Study IV,** 60 patients were included. They filled in a structured diary daily during six months in order to collect information about symptoms and potential trigger factors, such as perceived stress.

Results: No difference could be found in health-related quality of life between patients with ulcerative colitis and Crohn's disease. Scores of health-related quality of life were lower for patients with short disease duration than for patients with long disease duration. Patients with Crohn's disease and short disease duration had the lowest health-related quality of life. After attending an education programme, an improvement was found in the intervention group when measurements were made after one month. After six months, no improvement could be shown in health-related quality of life when comparing the intervention group with the control group. The RFIPC is the most appropriate choice when measuring health-related quality of life, worries and concerns. Using the single-factor model (sum score) displayed poor fit indices. The factorial structure of the RFIPC, as suggested in the original version, could be replicated with a slight modification in the Swedish version and showed the most adequate fit. Perceived stress can act as a trigger for relapses in inflammatory bowel diseases. High level of stress one day increased the risk of relapse the next day.

Conclusion: CD patients with short disease duration have the greatest need of education and support. No improvement could be seen in health-related quality of life after attending an education programme. The separate factors in RFIPC provide more detailed information about patients' disease-related worries and concerns in both research and clinical settings. This may help healthcare professionals to provide each patient with the appropriate education and support. Identification of trigger factors for relapses also makes it possible to influence the trigger. By extension, this could decrease the number of relapses and improve health-related quality of life.

Keywords: Inflammatory bowel disease, Crohn's disease, ulcerative colitis, health-related quality of life, worries, stress