

Adolescents' and their parents' experiences of inflammatory bowel disease – with focus on health, self-esteem and self-management

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Abstract

Inflammatory bowel disease (IBD) is a chronic and relapsing disorder of the gastrointestinal tract that includes the two major subcategories ulcerative colitis and Crohn's disease. Suffering from IBD during adolescence, which is a critical period of physical, psychological and social development, may be especially demanding and it may have adverse effects on self-esteem and socialization. The overall aim of this thesis was to explore and describe the experiences of adolescents with IBD and their parents with focus on health, self-esteem and self-management.

The setting for all four studies was one paediatric gastroenterology centre in Sweden. In study I, interviews were conducted with seventeen adolescents in order to explore experiences of interactions with their parents. By using a questionnaire in study II, the self-esteem in 71 adolescents with IBD was compared with healthy peers in order to identify risk factors. In study III, 116 parents of 66 adolescents filled in a disease-specific questionnaire, designed to explore the parents' views and the degree to which they agreed about their child's current and future health and family functioning in daily life. In study IV, 67 adolescents described their perceptions of well-being, self-management and disease impact in daily life, in written comments combined with a VAS measure.

In general, adolescents and their parents reported high well-being and satisfactory self-management. A subgroup with a severe disease course and/or separated parents was at risk for impaired health, low self-esteem and greater impact of IBD in daily life. The parent couples' views on their adolescent's current health status showed greater concurrence than their views about their child's future health. Furthermore, ambivalence was the most distinctive theme in the way in which adolescents described how they felt about their parents' response to their disease. Findings indicate that adolescents' self-esteem and general well-being is related to the way in which they perceive and handle their disease in daily life. In conclusion, increased awareness of conflicting attitudes, reactions and emotions in these families might help health care professionals to support adolescents with IBD and their parents.

Keywords: adolescents, parents, family perspective, inflammatory bowel disease, health, self-esteem, self-management, multimethod design, questionnaire, interview