Institutionen för neurobiologi, vårdvetenskap och samhälle

Familial Adenomatous Polyposis

A patient perspective on life after surgery

AKADEMISK AVHANDLING
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ABSTRACT

Familial adenomatous polyposis (FAP) is a rare hereditary condition with a high risk of gastrointestinal cancer. Individuals with FAP are committed to endoscopic screening surveillance throughout life in addition to having to undergo removal of the colon. With the intention to find strategies to develop care and support, the overall aim was to gain a deeper understanding of the life of surgically treated individuals with FAP. The first study used focus group interviews to collect data. The sample consisted of 14 surgically treated individuals, aged 18-75. Studies II-IV employed a cross-sectional design and were based on self-reported standardized questionnaires to measure abdominal symptoms, health-related quality of life, illness perceptions and quality of care. Assessments were performed using the Abdominal Symptom Questionnaire (ASQ), the Medical Outcomes Study Short Form 36 Health Survey (SF-36, the Revised Illness Perception Questionnaire (IPQ-R) and the Quality of Care from the Patients Perspective (QPP). The sample consisted of 209 surgically treated individuals, aged 18-75 (response rate 76%). The focus group interviews revealed that surgically treated individuals’ have several concerns, including issues about hereditary, the life-long nature of their illness and abdominal symptoms. Individuals use different strategies to minimize the effects of their illness on everyday life. The results from the self-reported questionnaires revealed that 91% of the individuals perceived at least one abdominal symptom during the past three months and reported a mean of 7 (SD 4.61; range 1-18) symptoms. A high number of abdominal symptoms predicted poorer health status. Furthermore, individuals perceived FAP as chronic and to a low extent possible to control. Negative consequences of the illness predicted a worse HRQL as did number of abdominal symptoms. Individuals receiving specialized care and those with a low number of abdominal symptoms were more likely to perceive the quality of care they received as better. In conclusion, to improve HRQL abdominal symptoms and negative consequences on life should be monitored and self-care supported when caring for surgically treated individuals with FAP. Care should be provided by a team of health-care professionals specialized in FAP and is recommended to be coordinated by a nurse. Such care should be holistic and focus on supporting the self-care of the individual.

Keywords: Abdominal symptoms; Chronic illness experience; Colorectal surgery; Familial adenomatous polyposis; Heredity; Health-related quality of life; Illness perception; Quality of care