

A "new life" with a stoma and quality of care among patients and their partners!

ABSTRACT

Information, education, and counselling are essential elements in stoma care. It is therefore important to take the necessary time to explain to patients and their partner what to expect when living with a stoma.

Aim: To describe the perception that patients and their spouses have of their life situation after stoma surgery, with particular emphasis regarding their personal views on the importance of various aspects of care and how they felt about the quality of care that was provided.

Methods: Nine patients were interviewed about their feelings and life experiences 6-12 weeks after stoma surgery. A qualitative method was used to collect and analyse the data. In addition to the interview procedure, quality of care of patients and their relatives was assessed using the identity-oriented dimension of the well-established questionnaire "Quality of Care from the Patients' Perspective". A colostomy group of 49 patients and 32 couples and an ileostomy group of 42 patients and 28 couples completed the questionnaire. Focus group interviews comprised of spouses to patients after surgery for rectal cancer were conducted as method of data collection. Qualitative content analysis was used to analyse the implicit meanings embedded within the interview material.

Results: The altered body image had an adverse impact on the sexual life of the patients and their spouses. Social life and leisure activities were also affected adversely and thus the couples had to adapt to their new live style accordingly. The topics covered by the questionnaire were considered important to both the patients and their relatives. Information given on results from medical examinations and laboratory tests was judged to be unsatisfactory in about one-half of the ileostomy patients and their relatives and in about one-third of the patients and their relatives in the colostomy group. Furthermore, their dissatisfaction with the possibility of participating in the decision-making process or to discuss sexual matters was even greater. Although the majority of the patients in both study groups considered the attitudes of the ET nurse and the treatment they received as satisfactory, the relatives were observed to be less content with these issues. Ileostomy patients and their relatives tended to be more displeased with the quality of care than the colostomy patients and their relatives.

Conclusion: Despite access to stoma therapy and modern stoma appliances, an ileostomy as well as a colostomy, were found to adversely affect the daily life of patients and their family. Concerning the quality of care, a large discrepancy still exists between what form of care is offered and what is actually given, particularly regarding patient participation and information needs. An attitude change that is more accommodating and that encourages spouses and relatives to take part in consultations might serve to facilitate the ostomy patient's long-term adjustment to living with a stoma.

Key words: Body image, Enterostomy, Information, Participation, Relatives, Quality of care.

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