

SUBJECTIVE RECOVERY FOLLOWING COLORECTAL CANCER TREATMENT

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien vid Göteborgs universitet kommer att offentligens försvaras i Hörsal 2118, Arvid Wallgrens backe, Hus 2, Göteborg, fredagen den 13 april 2018, kl 13.00

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Avhandlingen baseras på följande delarbeten

- I. Johansson, A-C., Axelsson, M., Berndtsson, I., & Brink, E. (2015). Self-reorientation following colorectal cancer treatment - a grounded theory study. *The Open Nursing Journal*, 9, 20-26.
- II. Johansson, A-C., Axelsson, M., Berndtsson, I., & Brink, E. (2014). Illness perceptions in relation to experiences of contemporary cancer care settings among colorectal cancer survivors and their partners. *International Journal of Qualitative Studies on Health and Well-being*, 9, 23581.
- III. Johansson, A-C., Axelsson, M., Grankvist, G., Berndtsson, I., & Brink, E. Symptoms, illness perceptions, self-efficacy and health-related quality of life following colorectal cancer treatment. Submitted.
- IV. Johansson, A-C., Brink, E., Cliffordson, C., & Axelsson, M. The function of fatigue and illness perceptions as mediators between self-efficacy and health-related quality of life during the first year after surgery in persons treated for colorectal cancer. In press, in *Journal of Clinical Nursing*.

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ABSTRACT

As a basis for nursing support for survivors and partners following CRC treatment, the overall aim of the present thesis was to explore the first year of subjective recovery following such treatment. First, the focus was on illness perceptions and self-reorientation in cancer care settings from the survivors' perspective as well as on cancer care settings and illness perceptions from the partners' perspective. Second, the focus was on investigating relations between fatigue, mental health, gastrointestinal health, illness perceptions and self-efficacy in relation to maintaining everyday activities, where health-related quality of life (HRQoL) was the outcome measure.

Persons treated for CRC at a county hospital in western Sweden and their partners were the participants. In Study I (n=17), III (n=46) and IV (n=39) the participants were survivors, and in Study II (n =18) the participants were survivors and partners. In Study I and II, data were collected through interviews and analyzed using Grounded Theory methodology. In Study III and IV, data were collected through questionnaires and statistically analyzed. The following questionnaires were used: European Organization for Research and Treatment of Cancer's (EORTC) cancer-specific Quality of Life Questionnaire (QLQ-C30); the Hospital Anxiety and Depression Scale (HADS); the Illness Perception Questionnaire-Revised (IPQ-R); and the Maintain Function Scale.

In Study I, the theoretical model explained self-reorientation as the individual trying to achieve congruence in self-perception. The core of self-reorientation was questions that did not have clear answers. Not knowing the cause of cancer, or not being able to understand bodily reactions, meant losing one's former sense of self. In Study II, the theoretical model illustrated illness perceptions of survivors and partners in relation to the experienced contemporary cancer care environment. Information and non-continuity was experienced as troublesome if there was no specific healthcare professional to contact if needed, and the time after discharge was characterized by loneliness. Survivors' and partners' illness perceptions were incompatible: Survivors tended to minimize the seriousness, while partners were more focused on seeing cancer as a life-changing event. In Study III, fatigue and diarrhea were identified as negative predictors of HRQoL, while self-efficacy in relation to maintaining everyday activities was identified as a positive predictor. The Maintain Function Scale was suitable for assessing self-efficacy in relation to maintaining everyday activities. Study IV showed a significant decrease in level of self-efficacy at 12 months. Emotional representations and fatigue, respectively, functioned as mediators between self-efficacy and HRQoL.

In conclusion, nurse-led follow up consultations after discharge need to be prioritized after treatment for CRC. Because illness perceptions not only influence self-reorientation but also function as a mediator between self-efficacy in relation to maintaining everyday activities and HRQoL, illness perceptions and self-efficacy need to be in focus when addressing symptoms. In addition to prioritizing nursing care after discharge, the informational burden, lack of continuity and strain on partners found in the results should be addressed during treatment.

Keywords: Cancer care, colorectal cancer, fatigue, grounded theory, health-related quality of life, illness perceptions, nursing, partners, path analysis, recovery, self-efficacy, self-reorientation.