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Publications

Douma KFL, Bleiker EMA, Aaronson NK, Cats A, Gerritsma MA, Gundy CM, Vasen HF. *Long-term compliance with endoscopic surveillance for familial adenomatous polyposis (FAP)*. *Colorectal Dis*. 2010;12:1198-207

Douma KFL, Aaronson NK, Vasen HFA, Gerritsma MA, Gundy CM, Janssen EPA, Vriends AHJT, Cats A, Verhoef S, Eveline Bleiker. *Psychological distress and use of psychosocial support in familial adenomatous polyposis*. *Psychooncology* 2010;19:289-98

Douma KFL, Aaronson NK, Vasen HFA, Verhoef S, Gundy CM, Bleiker EMA. *Attitudes towards genetic testing in childhood*

HEALTH-RELATED QUALITY OF LIFE ASSESSMENT AND BEHAVIORAL INTERVENTIONS IN CLINICAL ONCOLOGY

This research line has two primary foci: (1) development of methods and applications of health-related quality of life (HRQL) assessment in clinical research and clinical practice; and (2) development and testing of behavioral and psychosocial interventions to reduce symptom burden and improve the HRQL of patients with cancer.

Methods and measures for assessing the HRQL of mid- to long-term survivors of testicular and prostate cancer

This collaborative study between the EORTC Quality of Life and Genito-Urinary Cancer Groups has two primary objectives: (1) to test the logistics required to conduct survivorship studies within the context of the EORTC, with specific focus on long-term follow-up of patients treated in phase III clinical trials; (2) to pilot test questionnaires for assessing the HRQL of mid- to long-term cancer survivors (> 5 years disease free). Approximately 140 patients will be recruited from each of two EORTC GU Group phase III clinical trials – one in testicular and one in prostate cancer. The two samples will be drawn from three broad geographic/cultural regions: (1) Northern Europe; (2) Southern Europe; and (3) the United Kingdom. HRQL will be assessed at 3 levels: (1) generic (the SF-36 Health Survey); (2) cancer-specific (the EORTC QLQ-C30 plus condition-specific modules; and (3) cancer survivor-specific (the Impact of Cancer questionnaire). In 2010, IRB approval was obtained and data collection was initiated in the Netherlands, Norway, France, and Italy. IRB approval is pending in Belgium and the UK.

A randomized controlled trial of exercise training in hematological cancer patients following peripheral blood stem cell transplantation

This RCT, carried out by R. Knols, a PhD student of ours in Zurich, Switzerland, evaluated the effects of a 12-week outpatient physical exercise program, incorporating aerobic and strength exercises (n = 64), as compared to a usual care control condition (n = 67) on hematopoietic stem cell transplantation (HSCT) patients' physical performance and psychosocial well-being. Primary outcomes were quantified physical performance and self-reported physical functioning. Secondary outcomes were body composition measurement, quantified walking activity and patient-reported outcomes (physical activity, fatigue and health-related quality of life). Assessments were at baseline, immediately after program completion and at 3-month follow-up. Significant intervention effects were observed at both post-treatment and follow-up on physical performance measures. No other outcomes yielded statistically significant group differences.

A randomized controlled study of the efficacy of graduated compression stockings for prevention of lymphedema after inguinal lymph node dissection

graduated compression stockings have been advocated for prevention of lymphedema after inguinal lymph node dissection. Scientific evidence of their efficacy is lacking. In this RCT, 80 patients (45 with melanoma, 35 with an urogenital tumor) who underwent ILND were randomly allocated to compression stocking use for six months or to an usual care control group. No significant differences were observed between groups in the incidence of edema, the median time to the occurrence of edema, incidence of genital edema, frequency of complications, HRQL or body image. This study was unable to demonstrate the efficacy of prophylactic use of PhDd compression stockings for prevention of lymphedema after inguinal node dissection.

Cognitive behavioral therapy and physical exercise for climacteric symptoms in breast cancer patients experiencing treatment-induced menopause

This multicenter, randomized trial is evaluating the effectiveness of cognitive behavioral therapy (CBT), physical exercise (PE) or the combination of CBT/PE in alleviating climacteric symptoms in breast cancer patients experiencing treatment-induced menopause. 422 women were randomized to one of four groups: CBT, PE, CBT+PE or usual care. Preliminary results based on short-term (immediate post-intervention) follow-up indicate that both CBT and PE significantly improve menopausal and urinary symptoms, and sexuality, as compared to usual care. No significant program effects were observed for secondary outcomes, including body image. Neither CBT nor PE significantly influenced body image, psychological well

Key publications (continued)

and reproductive decision-making for familial adenomatous polyposis (FAP). *Eur J Human Genetics* 2010;18:186-93

Douma KFL, Bleiker EMA, Vasen HFA, Gundy CM, Gerritsma MA, NK Aaronson. *Quality of life and consequences for social life of familial adenomatous polyposis*. *Colorect Dis* 2010

Gundy CM, Aaronson NK. *Effects of mode of administration (MOA) on the measurement properties of the EORTC QLQ-C30: a randomized study*. *Health Qual Life Outcomes*. 2010;8:35

Lammens CRM, Bleiker EMA, Verhoef S, Hes FJ, Ausems MGE, Majoor-Krakauer D, Sijmons RH, van der Luijt RB, van den Ouweland AMW, van Os T, Hoogerbrugge N, Gomez-Garcia EB, Dommering CJ, Gundy C, Nagtegaal T, Aaronson NK. *Psychosocial impact of Von Hippel-Lindau disease: levels and sources of distress*. *Clin Genet* 2010;77:483-91

Hilarius DL, Kloeg PH, van der Wall E, Komen M, Gundy CM, Aaronson NK. *Cancer-related fatigue: Clinical practice versus practice guidelines*. *J Support Care Cancer* 2010

Knols RH, de Bruin ED, Uebelhart D, Aufderkampe G, Schanz U, Stenner-Liewen F, Hitz F, Taverna C, Aaronson NK. *Effects of an outpatient physical exercise program on hematopoietic stem-cell transplantation recipients: a randomized clinical trial*. *Bone Marrow Transplant (in press)*

Lammens CRM, Aaronson NK, Verhoef S, Wagner A, Sijmons RH, Ausems MGEM, Vriends AHJT, Ruijs MWG, van Os TAM, Spruijt L, Gomez-Garcia EB, Kluijt I, Nagtegaal T, Bleiker EMA. *Genetic testing in Li-Fraumeni Syndrome: Uptake and psychosocial consequences*. *J Clin Oncol* 2010;28:3008-14

van der Poll-Franse LV, Mols F, Gundy CM, Creutzberg CL, Nout RA, Verdonck-de Leeuw IM, Taphoorn MJ, Aaronson NK. *Normative data for the EORTC QLQ-C30 and EORTC-sexuality items in the general Dutch population*. *Eur J Cancer (in press)*

Taphoorn MJB, Claassens L, Aaronson NK, Coens C, Mauer M, Osoba D, Stupp R, Mirimanoff ROM, van den Bent MJ, Bottomley A. *An international validation study of the EORTC brain cancer module (EORTC QLQ-BN20) for assessing health-related quality of life and symptoms in brain cancer patients*. *Eur J Cancer* 46 2010:1033-1040

being or other aspects of HRQL. Long-term (6-month follow-up) results are currently being evaluated.

Physical exercise during chemotherapy to improve physical fitness and reduce fatigue (PACES) This multicenter, RCT is evaluating the effectiveness of two physical exercise interventions in maintaining or enhancing physical fitness and in minimizing fatigue in patients undergoing adjuvant chemotherapy for breast or colon cancer: (1) a low intensity, home-based, self-management program; and (2) a moderate intensity, structured, supervised program. In total, 360 patients will be randomized to one of the two intervention groups or to a usual care control group. All participants undergo performance tests and complete self-report questionnaires at baseline, at the completion of chemotherapy, and at 6 month follow-up. Patient recruitment started in the first quarter of 2010.

Behavioral and psychosocial effects of rapid genetic counseling and testing (RGCT) in newly diagnosed breast cancer patients This multicenter, RCT, carried out in collaboration with the University Medical Center Utrecht (Dr. Margreet Ausems), is investigating the uptake of RGCT when offered routinely to newly diagnosed breast cancer patients who, prior to receiving primary treatment, are identified as having at least a 10% risk of carrying a mutation in the BRCA1 or BRCA2 gene, and the impact of RGCT on a range of outcomes. Women (N = 255) recruited from 11 hospitals in the Amsterdam and Utrecht regions of the Netherlands are randomized to either RGCT or usual care (2:1 ratio). The study endpoints include: (1) uptake of RGCT; (2) choice of clinical management strategy, including direct bilateral mastectomy or delayed preventive contralateral mastectomy; (3) cancer risk perception and cancer-related distress; (4) knowledge of genetic aspects of breast cancer; (5) decisional satisfaction; (6) HRQL; and (6) satisfaction with RGCT. Questionnaires are administered at study entry, and at 6 and 12 month follow-up. All 255 patients have now been recruited into the study. Data collection will continue through 2011.

Predictors of neuropsychological improvement following cognitive rehabilitation in patients with gliomas This study investigated the specific patient-related factors that predict responsiveness to a cognitive rehabilitation program that has previously been demonstrated to be successful at the group level in patients with gliomas. Four categories of possible predictors of improvement were selected for evaluation: socio-demographics, clinical variables, self-reported cognitive symptoms, and objective neuropsychological test performance. Nearly 60% of the participants were classified as reliably improved. Reliable improvement was predicted by (younger) age ($p = .003$) and (higher) education ($p = .011$). Cognitive rehabilitation programs should take these patient characteristics into account and, if possible, adapt programs to increase the likelihood of improvement among older and less well educated participants.

Chemotherapy-induced nausea and vomiting (CINV) in daily clinical practice: A community hospital-based study This multicenter, observational study investigated: (1) the impact of CINV on patients' (HRQL) in daily clinical practice; (2) the association between patient characteristics, type of antiemetics and CINV; and (3) the role of CINV in decisions to modify antiemetic treatment. During three consecutive chemotherapy cycles, 277 patients used a diary to record emesis episodes and antiemetic use on the day prior to and 7 days after having received chemotherapy. Acute and delayed nausea during the first treatment cycle were reported by 39% and 68% of the patients, respectively. The comparable figures for acute and delayed vomiting were 12% and 23%. During the first and subsequent treatment cycles, approximately one-third of the patients indicated that CINV had a substantial impact on their daily life. At all treatment cycles, patients receiving treatment with moderately emetogenic chemotherapy containing anthracycline reported more acute nausea than patients receiving highly emetogenic chemotherapy. Acute vomiting was associated significantly with change in (i.e., additional) antiemetic treatment.