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Self-reported symptoms of faecal incontinence among long-term gynaecological cancer survivors and population-based controls

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ABSTRACT

Aim of the study: To make a comprehensive, detailed inventory of gastrointestinal symptoms reported by gynaecological cancer survivors and control women from the general population.

Method: We identified a cohort of 789 eligible women in the Stockholm and Gothenburg areas, treated with pelvic radiotherapy during the period 1991–2003, alone or as combined treatment, for gynaecological cancer. As controls, we randomly recruited 478 women, frequency matched by age and residence from the Swedish Population Registry. We collected data in 2006 by means of a study-specific, validated, postal questionnaire including 351 questions covering symptoms from the pelvic region. We asked about demographics, psychological and quality-of-life issues as well as social functioning.

Results: Participation was 78% for cancer survivors and 72% for controls. Mean follow-up was 7.2 years. In this large, population-based study, the greatest age-adjusted absolute risk difference between cancer survivors and control women was observed for the symptom defaecation urgency with faecal leakage and the highest age-adjusted relative risk for emptying of all stools into clothing without forewarning.

Conclusions: Cancer survivors having undergone pelvic radiotherapy alone or as part of combined treatment between the period 1991–2003 for a gynaecological malignancy had a higher occurrence of long-lasting gastrointestinal symptoms as compared to population controls.

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1. Introduction

In Sweden approximately 30,000 women are gynaecological cancer survivors[1] and many of them have received pelvic radiotherapy as part of cancer treatment. Gastrointestinal symptoms following pelvic radiotherapy are common and well documented,[2–6] but self-reported descriptions of gastrointestinal symptoms among long-term gynaecological cancer survivors are rare in the literature.

Prospective studies of gastrointestinal morbidity have used various instruments for recording and monitoring acute and late treatment-related effects after pelvic radiotherapy.[7–11] Although these scoring systems are applicable in comparing treatment arms in clinical trials, they lack self-reported descriptions of gastrointestinal symptoms and therefore, detailed distinctions between symptoms. Few studies report long-term morbidity exceeding 3–5 years after completed therapy.

Advances in gynaecological cancer treatment have resulted in improved survival and the number of cancer survivors has increased accordingly.[1] Long-term cancer survivors will therefore constitute a growing proportion of the general population seeking health-care outside oncology centres. In-depth knowledge of existing long-lasting symptoms and their influences on social functioning and quality-of-life is increasingly important for health-care providers.

Personal identity numbers and population-based registers in Sweden allow us to follow cancer survivors long after therapy and without selection-induced problems. We have performed a large population-based study on long-lasting symptoms after pelvic radiotherapy, given alone or as part of combined treatment, among gynaecological cancer survivors encompassing physical symptoms, demographics, psycho-sexual issues and social functioning. We here report an inventory of self-reported detailed descriptions of gastrointestinal symptoms and relate the reported occurrence to women from the general population.

2. Patients and methods

2.1. Study population

We identified a cohort of 1800 women treated between 1991 and 2003 with external pelvic radiotherapy for a gynaecological malignancy at Radiumhemmet, Karolinska University Hospital in Stockholm, and at Jubileumskliniken, Sahlgren ska University Hospital in Gothenburg of whom 1303 were alive in 2004. When excluding patients who did not meet the eligibility criteria, i.e. born 1927 or later, could read and understand Swedish and without recurrence of their malignancy, 789 patients remained and were included in the study (Fig. 1).

As controls we randomly recruited 486 women from the Swedish Population Registry, matched by age and place of residence. An error in the matching procedure led to a younger control population, which was adjusted for in the analyses. Exclusion criteria were previous radiotherapy to the pelvic region and inability to understand Swedish (Fig. 1). Women with prior abdominal surgery or malignancy other than a gynaecological cancer were allowed to participate. The regional ethics committees approved the study.

2.2. Questionnaire development

During an 18-month qualitative phase, which included 26 interviews, we constructed a study-specific questionnaire. The questionnaire was tested in a pilot study and was followed by the data collection, January–October 2006. The method used is well founded and has been described in several previous publications.[12–16]

2.3. Interviews

The gynaecological cancer survivors, who had undergone radiotherapy to the pelvic region 2–10 years earlier, were asked to participate in an interview at a routine follow-up. The interviews had no time limitation and were performed by the first author in a semi-structured way, focusing on the woman's current symptoms, quality-of-life and social functioning. A secretary prepared word-by-word transcripts from the interview recordings.

After interviewing 26 gynaecological cancer patients, no new information was identified. The reported symptoms were transformed into questions and sorted as follows: physical symptoms from the gastrointestinal area, bladder, genitals, pelvic bones and legs, as well as psychological symptoms, quality-of-life and social functioning. Additional questions from previous studies within the research unit were added to a first draft of the study-specific questionnaire.

2.4. Instruments

In each part of the study-specific questionnaire we asked about the incidence, prevalence, intensity and duration of the symptoms when appropriate. For example: '*Have you emptied all stools into your clothes without forewarning during the past six months?*' with the following possible answers: '*No*', '*Yes, occasionally*', '*Yes, at least once every month*', '*Yes, at least once a week*', '*Yes, at least three times a week*', '*Yes, at least once a day*'.

2.5. Validation

The study-specific questionnaire was validated within the study-population with 20 women, using face-to-face validity. Based on their comments the questions were revised and a new draft was completed. The final questionnaire consisted of 351 questions divided as follows: the first part covered demographic data, information about the disease and its treatment. The second part included questions on psychological issues such as self-assessed anxiety and depression, quality-of-life, physical health and social functioning including relations to family and friends. In parts 3–8 we asked for information concerning the physical symptoms and the participant's sexuality.

In a pilot study including 20 other individuals from the study population, we tested the questions, the participation rate for completing the questionnaire, the response rate on