

## Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: A study from the population-based PROFILES registry

Kim Agnes Helma Nicolaije<sup>a,b,\*</sup>, Olga Husson<sup>a,b</sup>, Nicole Paulina Maria Ezendam<sup>a,b</sup>, Maria Caroline Vos<sup>c</sup>, Rutgerus Franciscus Petrus Maria Kruitwagen<sup>d</sup>, Marnix Lodewijk Maria Lybeert<sup>e</sup>, Lonneke Veronique van de Poll-Franse<sup>a,b</sup>

<sup>a</sup>CoRPS – Center of Research on Psychology in Somatic Diseases, Department of Medical Psychology and Neuropsychology, Tilburg University, The Netherlands

<sup>b</sup>Eindhoven Cancer Registry, Comprehensive Cancer Center South (CCCS), The Netherlands

<sup>c</sup>Department of Obstetrics and Gynecology, St. Elisabeth Hospital, Tilburg, The Netherlands

<sup>d</sup>Department of Gynecology and GROW – School for Oncology and Developmental Biology, Maastricht University Medical Center, Maastricht, The Netherlands

<sup>e</sup>Department of Radiotherapy, Catharina Hospital, Eindhoven, The Netherlands

### ARTICLE INFO

#### Article history:

Received 30 January 2012

Received in revised form 27 April 2012

Accepted 2 May 2012

#### Keywords:

Endometrial cancer  
Cancer survivors  
Information provision  
Information satisfaction  
Population-based  
PROFILES registry

### ABSTRACT

**Objective:** To evaluate perceived level of and satisfaction with information received by endometrial cancer survivors, and to identify associations with socio-demographic and clinical characteristics.

**Methods:** All patients diagnosed with endometrial cancer between 1998 and 2007, registered in the Eindhoven Cancer Registry, received a questionnaire including EORTC-QLQ-INFO25.

**Results:** Seventy-seven percent responded ( $n = 742$ ). Most patients indicated receiving quite a bit information about their disease and medical tests. However, most patients were not (54%) or a little (24%) informed about the cause of their disease, and possible side effects (36%; 27%). Especially information about additional help, rehabilitation, psychological assistance, and expected results on social and sexual life was lacking. Five percent was not or a little (36%) satisfied. Four percent found the information not or a little (35%) helpful. Fifteen percent preferred more information. Younger age, more recent diagnosis, radiotherapy, absence of comorbidities, having a partner, having received written information, and higher educational level were associated with higher perceived information receipt.

**Conclusion:** Many endometrial cancer survivors are unsatisfied with received information. Several areas of information provision are experienced as insufficient.

**Practice implications:** More patient-tailored information is probably needed to provide optimal information. Implementation of Survivorship Care Plans might be a way to achieve this.

© 2012 Elsevier Ireland Ltd. All rights reserved.

## 1. Introduction

Endometrial cancer is the most frequent gynecological cancer in industrialized countries, with an incidence of 15–25 per 100,000 women per year [1,2]. An ageing population with more diagnoses of endometrial cancer, increased risk factors, such as obesity, diabetes, and a lower parity, and more aggressive treatments in advanced disease all have resulted in increasing numbers of endometrial cancer survivors. In 2005, there were about 17,000 endometrial cancer survivors in The Netherlands, and this number is expected to increase to 25,000 in 2015 [3].

Patient information is an essential factor in the support for cancer survivors across the whole cancer trajectory. Appropriate information given to cancer survivors about their diagnosis, treatment, possible long-term and late effects and referral services can result in better informed decision making, lower levels of distress, and improved satisfaction with care and sense of control [4–7]. Cancer survivors who are satisfied with the information they received have a better health related quality of life, and lower levels of depression and anxiety [8]. Studies suggest that most cancer patients want as much information as possible [7,9,10]. However, the information needs of cancer patients differ by gender, age, cultural background, educational level, cancer type, stage of disease (at diagnosis, treatment and follow-up), and coping style [11,12]. Understanding factors associated with information provision might help health care providers to provide more patient-centered information by giving adequate information to those who need it, at the right time [13].

\* Corresponding author at: CoRPS, Department of Medical Psychology and Neuropsychology, Tilburg University, Warandelaan 2, PO Box 90153, 5000 LE Tilburg, The Netherlands. Tel.: +31 13 466 2299; fax: +31 13 466 2175.

E-mail address: [K.A.H.nicolaije@uvt.nl](mailto:K.A.H.nicolaije@uvt.nl) (K.A.H. Nicolaije).

Previous research has shown that likelihood of cure, information on (spread of) disease, and side effects of treatment are information needs of gynecological cancer survivors [14–16]. In addition, previous studies suggest that gynecological cancer survivors would appreciate more information concerning how the disease and treatment affect their self-image, sexuality [17], and fertility [18]. Identifying the specific information needs of endometrial cancer survivors might facilitate gynecologists, radiotherapists, medical oncologists, and oncology nurses in providing patient-centered information, which may contribute to improved quality of life of endometrial cancer survivors. However, until now, research investigating the specific information needs of endometrial cancer survivors is lacking. Investigating the current state of information provision and degree of satisfaction with information provision of endometrial cancer survivors is valuable to determine whether the current information provision is sufficient, or whether improvement is necessary. The present study therefore aims to assess the perceived level of and satisfaction with information received by endometrial cancer survivors, and to identify possible associations with socio-demographic and clinical characteristics.

## 2. Methods

### 2.1. Setting and participants

A cross-sectional study was performed among 1091 endometrial cancer survivors registered within the Eindhoven Cancer

Registry (ECR) of the Comprehensive Cancer Center South (CCCS). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands. The ECR was used to select patients diagnosed with endometrial cancer between January 1st 1998 and October 1st 2007 in 10 hospitals. All individuals (age 18–84 years) diagnosed with endometrial cancer FIGO stages I–II (classification 1988) were eligible for participation. Deceased patients were excluded by linking the ECR with the Central Bureau of Genealogy (Fig. 1). Ethical approval for the study was obtained from a Medical Ethics Committee.

### 2.2. Data collection

Data collection took place between May and July 2008 and was done within PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship). PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of both short and long-term cancer survivors. PROFILES contains a large web-based component and is linked directly to clinical data from the ECR. Details of the data collection method have been previously described [19,20]. Data from the PROFILES registry will be available for non-commercial scientific research, subject to study question, privacy and confidentiality restrictions, and registration ([www.profilesregistry.nl](http://www.profilesregistry.nl)).

Gynecologists sent their (former) patients a letter to inform them about the study and a questionnaire. To avoid coercion and

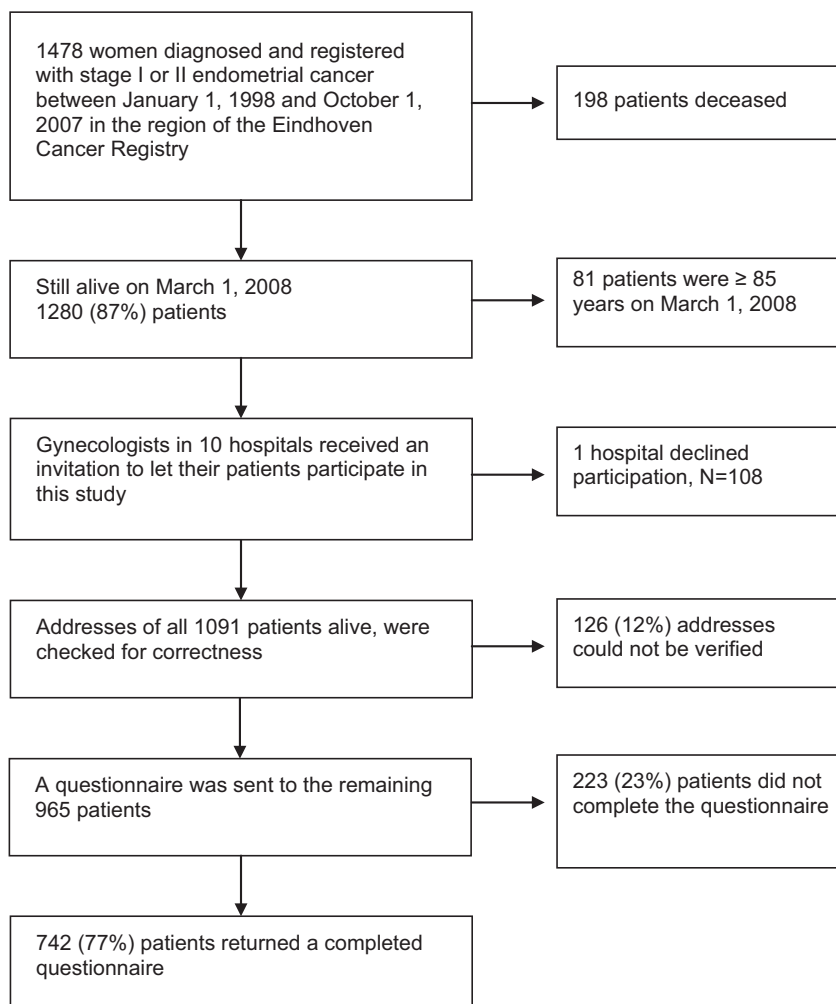


Fig. 1. Flow-chart of the data collection process.

Download English Version:

<https://daneshyari.com/en/article/3815170>

Download Persian Version:

<https://daneshyari.com/article/3815170>

[Daneshyari.com](https://daneshyari.com)